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Daily life restrictions in the care for people with moderate intellectual disability: perception and evaluation of support staff, relatives and people with moderate intellectual disability

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Chapter 1

General Introduction

1.1. Shift in paradigm

In the last decades, there has been a shift in the paradigm of care for people with intellectual disability: from a focus on substituted decision-making to supported decision-making. In the case of substituted decision-making a proxy makes decisions on behalf of another person who is incapable (Devi, Bickenbach, & Stucki, 2011; Suto, Clare, & Holland, 2002). The person concerned is not considered to be capable of making a decision for himself or herself. Supported decision-making however can be defined 'as a series of relationships, practices, arrangements, and agreements, of more or less formality and intensity, designed to assist an individual with a disability to make and communicate to others decisions about the individual's life' (Dinerstein, 2012, p. 10). Supported decision-making is based on the principle that all people are autonomous beings who develop and maintain capacity as they engage in the process of their own decision-making even if at some level support is needed (Devi et al., 2011). In the case of people with ID, they experience more often than people without ID a mismatch between their personal competences and environmental demands, resulting in a greater need of particular types of support. People with ID are often dependent on support provided by support staff (Thompson et al., 2009). In the supported decision-making paradigm, the person concerned should receive support from relatives, support staff, or other entities to make personal, financial, and legal decisions that must be followed by third parties such as financial institutions, business, health professionals, and care organizations (Bach, 2006). Depending on the needs and desires of the person with disability, the supporting person(s) will aid the person with disability to understand the relevant issues and information and make their own decisions based on his or her own preferences and wishes (Antaki, Finlay, Walton, & Pate, 2008). The paradigm of supported-decision making is supported in (inter)national policy, with for example the United Nations Convention on the Rights of Persons with Disabilities addressing the need to support people with disabilities: "States Parties shall take appropriate measures to provide access by persons with disabilities to the support they may require in exercising their legal capacity (UNCRP, 2012, article 12.3)". The focus in supported decision-making is on sustaining and helping people with disabilities to make their own choices (Devi, Bickenbach, &

Stucki, 2011).

1.2. Restrictions

In supported decision-making, it is the responsibility of the supporting person(s) to sustain people with ID to make their own choices, but it is also their task to protect people with ID from harm, as a consequence of which they may need to restrict them in making their own choices (Verkerk 2001). When people with ID protest against restrictions applied on them, these restrictions should be diminished, if possible, and there should be a search for alternatives (Act Care an Coercion, 2018; Heyvaert, Saenen, Maes, & Onghena, 2014a, 2014b; Mériniau-Côté & Morin, 2014). In the care for people with ID, most of the focus is on diminishing severe, often physical, restrictions such as isolation, enclosing, fixation and obliged use of medicaments (Hawkins, Allen, & Jenkins, 2005; Heyvaert et al., 2014a, 2014b). These restrictions have been found to be intrusive for people with ID, and are possibly reducing their well-being (Heyvaert et al., 2014a, 2014b; Mériniau-Côté & Morin, 2013). In addition, Heyvaert et al. (2014a) reported that the application of physical restrictions is just as compelling for people with ID as for support staff and relatives of people with ID. In addition, people with ID and support staff are not free from danger of injury or harm in enduring or applying severe physical restrictions (Luiselli, 2009; Williams, 2010). In the Netherlands, the physical restrictions on Jolanda Venema in 1988 (Andere Tijden, 2013) and Brandon in 2011 (Uitgesproken EO, 2011) lead to a greater awareness of the impact of these restrictions. In 1988, the parents of Jolanda Venema, a woman with severe intellectual disability, took pictures of their daughter, who was nude, and tied up on the bare wall of the living room in the care organization due to supposed challenging behavior. By taking pictures of her, Jolanda's parents wanted to make this intolerable situation public in order to improve Jolanda's and others' living conditions in care organizations for people with ID. The pictures of Jolanda had a great impact and the following societal discussion about severe restrictions in the care for people with ID lead to the creation of five regional consultation projects (Project Consulententeams, Canon Sociaal Werk, 2009) and finally to the establishment of the national center for consultation and expertise (CCE).

This center was founded to provide advice and expertise to professionals and families who were looking for ways to deal with the challenging behavior of their clients or family members with ID (Canon Sociaal Werk, 2009). Furthermore, the law that arranged for compulsory admission and treatment of among others people with ID with challenging behavior (Act BOPZ, 1994) was evaluated several times (Ministerie VWS, 2008). At the center of these evaluations was the recommendation to take the perspective of the care receivers into account when restricting is considered. In addition, it was concluded that for people with ID and people with a psycho-geriatric disorder, a new act, specific to this population, had to be prepared, since the Act BOPZ (1994) was primarily focused on people with a psychiatric disorder. However, in spite of all efforts to diminish restrictions, another incident arose in 2011. A television program paid attention to a young man named Brandon, who was tied up with a belt during most of the day for about three years (Uitgesproken EO, 2011). This severe physical restriction was placed on him due to his unpredictable and sometimes aggressive behavior. Like Jolanda Venema, Brandon's situation lead to severe criticism of the care organization he lived in and the wish to diminish physical restriction as much as possible. Therefore, in 2011 the Dutch Ministry of Health, Welfare and Sport initiated a taskforce that was assigned to provide policy recommendations on complex care situations in which professionals saw no alternative to applying severe physical restrictions on people with ID (Ministerie van VWS, 2012). One of the recommendations of the taskforce was, similar to earlier advices (Ministerie van VWS, 2008), to pay more attention to the opinions and perspectives of clients and their family members in interpreting the signals of challenging behavior (Ministerie van VWS, 2012; Actieprogramma Onvrijwillige Zorg, 2013). They should be more involved in the caring process. In addition, the Dutch Healthcare Inspectorate concluded that more dialogue between clients, family and professionals is needed when it comes to decisions about severe restrictions (IGZ, 2011). Next, the taskforce advised taking a multi-tiered approach in the care of people with ID and challenging behavior. Step-by-step care for people with ID and challenging behavior in the case of ongoing restrictions, has to be extended with the know-how of specialists with the aim of decreasing the restrictions as much and as soon as possible. In case of long-standing and intrusive restrictions of people with ID more

expertise from outside the care organization is required, according to the taskforce (Actieprogramma Onvrijwillige Zorg, 2013). This recommendation to take a multi-tiered approach has been adopted and has become a part of the new Care and Coercion Act (2018) which replaced the Act BOPZ (1994). After a lengthy process, the Care and Coercion Act was implemented in January 2020. The act addresses nine categories of so-called involuntary care, i.e., care against which clients or representatives protest: a) applying liquid, food and medication as well as applying medical controls or medical treatments and therapeutic measures in the treatment of a psychiatric disorder or intellectual disability, b) restricting the freedom of movement, c) enclosing, d) controlling the person concerned, e) investigating clothing or body, f) controlling the presence of remedies which influence the behavior of clients, g) controlling the use of conduct-changing medicine, h) applying measures to arrange the life of the person concerned in such a way that the person has to do or to stop doing something, including the use of means of communication, and i) restricting the right to receive visits. In the Care and Coercion Act the perspective of the client, or representative in case of mental incapacity of the client, is most important. If there is resistance from the client or representative to the application of one of the nine categories of care as mentioned in the act, care is perceived to be involuntary (Care and Coercion Act, 2018).

1.2.1. Evaluation of restrictions

In diminishing restrictions, the main focus is on severe, physical restrictions applied in the lives of people with ID and challenging behavior in complex care situations, but there is less focus on “mild” restrictions. The latter are often conducted by support staff and are common in the daily lives of people with ID, both for people with and without challenging behavior (Eye for Freedom, 2013; Dörenberg et al, 2018). Moreover, support staff often do not describe these actions as restrictions, but as pedagogical measures to support clients’ development (Dörenberg et al., 2018). The following case provides an

example of such a restriction. A support worker doubts what is good care with respect to the possible application of a restriction in the daily life of a client:

> "We have formally accepted that clients should be able to determine their own lives. That is a respectful goal, but at a certain moment, we were confronted with a boy who sat the whole day behind his computer eating pizza's and drinking coke. He was getting obese. Then you have to ask yourself the question: should we not have to intervene as support staff?" (Eye for Freedom, 2013).

Research indicates that support staff of people with mild ID evaluate rules like restricted times for meals, fixed bedtimes, or taking a shower as involuntary care. This counts for 53% of the support staff (NIVEL, 2013, p.14). In addition, support staff (87.8–96.8%) who work with adolescents with mild ID considered social restrictions, such as limiting the use of mobile phones, as justifiable in the case of danger, physical aggression, or sexually abusive behavior (Dörenberg et al., 2018). People with mild intellectual disability themselves may experience measures in daily care as restricting (Dörenberg, Embregts, Van Nieuwenhuijzen, & Frederiks, 2013; Heyvaert, Saenen, Maes, & Onghena, 2014a; b; Negenman, Embregts, De Bakker, Van Nieuwenhuijzen, & Frederiks, 2014). For example, they indicate to experience imposed rules regarding use of means of communication like laptop or mobile phone or regarding social contacts as involuntary (De Bakker, Van Nieuwenhuijzen, Negenman, Embregts, & Frederiks, B., 2014; De Veer, Dörenberg, Francke, Van Nieuwenhuijzen, & Embregts, 2013; Frederiks, Dörenberg, Van Nieuwenhuijzen, & Embregts, 2014; NIVEL, 2013).

As opposed to people with mild ID, who are able to verbally indicate how they experience restrictions, evaluation of restrictions in daily care of people with profound or severe ID (IQ 20-50/55), poses challenges. People with severe or profound ID possess little or no ability to support themselves and are dependent on others to explain the world around them and to make the world accessible (Poppes et al., 2016). Since people with severe or profound ID are severely restricted in expressing their wishes and needs, studies focus on proxies like support staff or relatives (Poppes et al., 2016;

Zijlstra & Vlaskamp, 2005). Furthermore, studies conducted amongst relatives and support staff of people with severe ID in which they are asked to take their perspective, show that they feel their relative/client with severe ID is unaware of applied restrictions and unconscious of the effects of these restrictions (Embregts, Negenman, Habraken, de Boer, Frederiks, & Hertogh, 2018; Hertogh et al., 2015). Only few measures were considered restricting by support staff and family, whilst asked to take the perspective of people with moderate to profound ID. Asked to take their own perspective, all applied measures were perceived as restricting by more than half of support staff and relatives however (Embregts et al., 2019).

1.3. Research population: People with moderate ID

Worldwide, intellectual disability affects about one percent of the population, out of which the majority (Maulik, Mascarenhas, Mathers, Dua, & Saxena, 2011) has a mild intellectual disability (ID 50/55-70, American Psychiatric Association, 1994). In the Netherlands there are approximately 142.000 people with ID (VGN, 2020), with an estimated number of 74.000 people having a mild intellectual disability. In the remaining group of 68.000 people, no distinction is made in the amount of people with a moderate, severe or profound disability (moderate ID 35-50/55, severe ID 20-35, profound ID < 20, American Psychiatric Associaton, 1994).

With the majority of people with an ID having a mild ID, the emphasis in research concerning restrictions in daily life is on people with mild ID, and to a lesser extent on people with severe or profound ID. Studies examining the perception of people with moderate ID on restrictions in daily life are scarce. Individuals with moderate ID have an IQ in the range of 35/40 – 50/55 with an estimated age of development between six and nine years old (American Psychiatric Association, 1994). People with moderate ID possess more abilities than people with severe ID. For example, they have more verbal capabilities to express their needs and desires than people with severe ID do. For people with moderate ID, independent living may be achieved with moderate levels of support, such as those

available in group homes (Jingree, Finlay, & Antaki, 2006). They can travel to familiar places in their community and join day-activities (Dusseljee, Rijken, Cardol, Curfs, & Groenewegen, 2011). They can also learn basic skills in relation to health and hygiene. Although they can express what they like or dislike in daily situations (Browder et al., 2013), when compared to people with mild ID, people with moderate ID are less able to express their own wishes and needs (American Psychiatric Association, 1994). People with moderate ID are in need of ongoing assistance in self-care and in conceptual tasks and decision-making (American Psychiatric Association, 2013). Deficits in intellectual functions, such as reasoning, problem-solving, planning, abstract thinking, and judgment are combined with deficits in adaptive functioning that result in failure to acquire personal independence (American Psychiatric Association, 2013; Tyrer et al., 2008). People with moderate ID are therefore dependent on the correct interpretation by relatives and support staff of behaviour and body language, which is often interpreted ambiguously (Van Dartel, 2007). To arrive at supported decision-making, people with moderate ID are thus to be sustained in this process by significant others.

1.3.1. Supportive networks

Support staff and relatives play a significant role in the supportive networks of people with moderate ID (Forrester-Jones et al., 2008). Almost all people with moderate ID receive some kind of professional support. In the Netherlands, people with moderate ID mostly live in residential settings with support from staff in many aspects of their daily lives (VGN, 2020). Staff do not only provide instrumental support to people with moderate ID, but they may also support them on an emotional level (Van Asselt-Goverts, Embregts, & Hendriks, 2013), and may provide meaningful social contact (Giesbers, Hendriks, Jahoda, Hastings, & Embregts, 2019). Support staff might even be experienced as key persons in the lives of people with moderate ID (Lippold & Burns, 2009).

In addition to support staff, relatives are often permanent agents in the lives of people with moderate ID (Knox, Parmenter, Atkinson, & Yazbeck, 2000). Relatives are often the main provider of

informal support to people with ID (Sanderson, Burke, Urbano, Arnold, & Hodapp, 2017), and they provide a unique type of support that is characterized by unconditional love, emotional closeness and long-term involvement (Bigby & Fyffe, 2012). Relatives might also act as advocates, information seekers, spokespersons, and public educators for their family members with ID (Dunst & Dempsey, 2007), and may be the primary source for expanding their social network to members in the local community, apart from the service provider (Overmars-Marx, Thomése, Verdonschot, & Meininger, 2014). Thus, in supporting people with moderate ID, support staff and relatives play a crucial role. As a consequence they are crucial partners in supported decision-making in general and specifically with respect to restrictions. Therefore, examining their view on whether or not to apply restrictions is pivotal. In other words, moral reflection on the perception and evaluation of daily life restrictions for people with moderate ID needs to incorporate the view of these important others, which will be covered in chapters 2 (support staff) and 4 (relatives). In addition, in chapter 5 and 6 the moral reflection of two teams of support staff on the application of restrictions will be examined. In addition to the view of support staff and relatives, it is pivotal to examine how people with moderate ID themselves evaluate restrictions in their daily lives (chapter 3). Exploring their perception and evaluation of restrictions may deepen the understanding of the extent to which people with ID agree or disagree with applied restrictions. In line with supported decision-making, it is essential to explore the perception and evaluations of clients themselves together with the view of support staff and relatives. For careful decision-making with regard to the application of restrictions, all three perspectives should be taken into account.

1.4. An ethics of care

Supported decision-making with regard to decisions about the application of daily life restrictions in care for people with ID, requires the engagement of relatives as well as support staff. With respect to support staff, the dependency of people with ID requires staff to be reliable, compassionate, as well as attuned and sensitive to the people they care for (e.g., Willems, 2016). In this respect, moral virtues like compassion, attentiveness, and sensitivity are essential and highly valued in the care for people with ID (Kittay, 2011; Meininger, 2001). Within an ethics of care, these are central notions. Therefore, an orientation on ethics of care forms the basis of this dissertation.

For a better understanding of an ethics of care, it is helpful to introduce two care-ethicists. The first is Joan Tronto, whose ethics of care stems from a political perspective. She states that care goes beyond the private domain. The second is Eva Kittay, who focuses specifically on people with ID. According to Tronto, care is "a particular or universal practice aimed at maintaining, continuing or repairing the world" (1993, p.104). In this respect, Tronto emphasizes the particular, contextual character of an ethics of care (Tronto, 1993; 2009). She refuses to work with a universalistic ethical theory, which in her view is not appropriate for analyzing political and societal systems. There is no universalistic compass to rely on. Therefore, Tronto starts from an overall concept of human interdependence (Tronto, 1993, p. 101). While human interdependence is Tronto's starting point, she considers moral sentiments such as kindness, attachment, and compassion as point of departure for her moral deliberations. In the process of care she discerns four phases. The first phase can be described as "*caring about"*: there is recognition that care has to be given to the care receiver. "*Taking care of"* represents the second phase, in which the responsibility for the identified need is recognized. In the third phase "*caregiving",* the caregiver makes contact with the care receiver. This phase entails the physical effort the caregiver has to make. In the last phase "*care receiving",* the caregiver takes notice of the fact that care has to be received. The care receiver has to respond to the care activity. According to Tronto, it is important to include care receiving as the last element of the caring process,

because it provides the only way to know whether the caring needs have actually been met. For the implication of these four phases of care, four virtues are listed: attentiveness ("caring about"), responsibility ("taking care of"), competence ("caregiving") and responsiveness ("care receiving"). Tronto's enumeration of phases is also helpful in analyzing caregiving for people with ID. It focuses on the primary process in the care for people with ID instead of focusing on programs, paradigms or controllability. Analyzing care for people with ID by means of an ethics of care encompasses in this respect "examining patterns of involvement, examining interactions between people, taking the significance of personal attachment into account and not focusing on incidents for new policies" (Embregts, 2009, p.16). Consequently, support staff are inspired to enter into social and emotional ties with their clients. This attitude of involvement is appreciated by care-receivers. Support staff are positively evaluated when they express a positive attitude, listen to clients, take them seriously, try to understand them, create time for them, provide practical help, can be trusted and are open and honest (Embregts, 2009, p.19). Van Heijst calls this an attitude of professional loving care (2011)

In reflecting on care for people with intellectual disability from the stance of an ethics of care, it is also interesting to look at the moral considerations of care ethicist Eva Kittay. She makes interesting and valuable points with respect to the care for people with ID, which are briefly mentioned here. Kittay specifically focuses on the care for people with ID. As a professor and mother of a daughter with severe intellectual disability, Kittay combines the academic world of rational, moral thinking with the world of caring for her severely disabled daughter (Kittay, 2009). In contrast to Tronto, Kittay does not build a moral framework. In her moral reflections, she states that it is best to acknowledge that dependency is a feature of all human life. People with ID especially have to deal with great dependency on others. In her view relationships between people with ID and caregivers, characterized by genuine caring and respect, have to be stimulated (Kittay, 2008; 2011). Such relationships provide space for the growth of people with ID. According to Kittay, it is only via compassionate relationships that people with ID are sustained and supported. All people are dependent on each other, especially people with a moderate or severe ID. Our dignity is bound both to our capacity "to care for" and in "being cared for". People

with a moderate or severe ID who do not always give clear responses to care, need help and sustainment to flourish (Carlson & Kittay, 2010).

To summarize, we depart in this dissertation from an ethics of care. The reason to start from this orientation is that ethics of care focuses on an active and committed role for support staff. They should not stand aside, but should build trustful relationships with their clients and be emotionally involved with them (e.g., Tonkens & Weijers, 1999; Van Heijst, 2011). Their engagement includes the support of clients in their decision-making. Together with relatives who should also be included in the process of decision-making (Kittay, 2009) support staff should play a role in supported decision-making for clients with respect to application of daily life restrictions.

1.5. Outline dissertation

In this dissertation, we explore how support staff, people with moderate ID and their relatives perceive and evaluate restrictions in daily life of people with moderate ID. To gain insight in these evaluations, we examined their views on application of restrictions. In this dissertation, the term restrictions is preferred over restraints, although the latter is used in chapter 2. In the ongoing process of analyzing and adjusting research items, which is inherent to qualitative research (Verschuren & Doorewaard, 2010), we felt it necessary to change from “restraints” to “restrictions”. The term “restraints” is often related to physical restraints such as fixation and separation against which clients protest (Heyvaert et al., 2015). Since our research focuses on “mild restraints” in daily care without a specific focus on physical interventions, the term “restrictions” seemed more suitable for the following chapters (chapter 3 to 7).

Studies are conducted on behalf of Elver, a care organization for people with ID in the eastern part of the Netherlands. All respondents within these studies were support staff, clients or relatives of clients affiliated to Elver.

This dissertation consists of the following chapters. In **chapter 2,** support staff's perception and evaluation of daily life restrictions on people with moderate ID is examined. For this study, 15 support staff were interviewed via semi-structured interviews. They were asked what they would describe as restrictive in daily life for people with moderate ID. Next, support staff were asked to provide justifications when restrictions were applied. They were also interviewed about the way they dealt with the application of restrictions. In **chapter 3,** people with moderate ID themselves were interviewed about the application of restrictions in their daily life. To explore their evaluation triangulation of sources (Boland et al., 2008) was used: eight people with moderate ID were interviewed several times a day, followed by interviews with their key support workers and reviews of their clinical files. In **chapter 4,** we present the results from the interviews of ten relatives of people with moderate ID. All relatives were representatives of their son, daughter, brother or sister and were authorized to make decisions for their family members with moderate ID.. Relatives are only operating as representatives in situations where the person with moderate intellectually disability is mentally incapable. To explore relatives' evaluation of restrictions, semi-structured interviews were conducted.

In addition to the evaluation of restrictions in the daily lives of people with moderate ID, we have investigated whether a practical tool used by support staff would be helpful in heightening staff's awareness of clients' perspective. Therefore, **chapter 5** explores moral case deliberation as an instrument to heighten staff's awareness of the perspective of people with moderate ID and help staff to deal with restrictions in a morally responsible way. Moral case deliberation can be defined as "the methodological reflection on concrete moral cases among health care professionals" (Molewijk, Verkerk, Milius, & Widdershoven, 2008), p. 43). By examining what is morally right in a specific care situation, moral case deliberation contributes to the improvement of the ethical climate and the moral quality of the care process. To the best of our knowledge, no evaluative research has been conducted on moral case deliberation a) in the daily care of people with ID, and b) with regard to daily life restrictions in the care for people with moderate ID. Three sessions of MCD per team within a six-week period were organized. Each session had an average duration of one hour and was audio-taped. The

MCD sessions took place within the same organization. In each MCD session a dilemma concerning a restriction in the daily life of a person with moderate ID was discussed. **Chapter 6** provides insight in the actual content of these Moral Case Deliberations held amongst the teams of support staff. Moral Case Deliberation is often a black box for outsiders. This brief report provides insights into what teams of support staff perceive and evaluate as good care regarding the application or diminishing of restrictions in daily lives of people with moderate ID.. In the general introduction, **chapter 7,** the findings of all studies are summarized and discussed. Additionally, directions and implications for care practice and future research are provided. Furthermore, the findings will be reflected upon in light of an ethics of care.

1.6. Research question and aims

To conclude, this dissertation explores "mild", commonly applied restrictions in the daily life of people with moderate ID such as restrictions in amount of food intake and bedtimes. In addition, we explore how support staff, people with moderate ID and their relatives evaluate these daily life restrictions and what justifications and strategies they use for applying restrictions. In all, the central research question of this dissertation is: **how do support staff, people with moderate ID themselves and relatives of people with moderate ID perceive and evaluate restrictions in the daily life of people with moderate ID?**

Providing an answer to this question is relevant, since a) little research is conducted on the evaluation of daily life restrictions applied to people with moderate ID specifically, and b) daily life restrictions are often not recognized as restrictions, because they are common in the lives of people with moderate ID. In addition they may be perceived as "mild" in contrast to severe physical restrictions, such as fixation or isolation.

The **aim** of this dissertation is twofold. First, in exploring the perspectives of of support staff, people with a moderate ID and their relatives on daily life restrictions for people with moderate ID, we

aim to contribute to the knowledge base of a category of restrictions, which has been the subject of *little research*, in an underexplored client population. Second, we aimed to contribute to the evidence underlying MCD in health care as an instrument to increase awareness of and sensitivity toward the client's perspective, which might be of assistance in supported decision-making in the care for people with a moderate ID.

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Chapter 2

Restraints in daily care for people with moderate intellectual disabilities

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Abstract

Background

Self-determination is an important factor in improving the quality of life of people with moderate intellectual disabilities. A focus on self-determination implies that restraints on the freedom of people with intellectual disabilities should be decreased. In addition, according to the Dutch Care and Coercion bill, regular restraints of freedom, such as restrictions on choice of food or whom to visit, should be discouraged. Such restraints are only allowed if there is the threat of serious disadvantage for the clients or their surroundings. Research question: What do support staff consider as restraints on freedom and how do they justify these restraints?

Research design

In this study, data were collected by semi-structured interviews.

Participants and research context

Fifteen support staff working with clients with moderate intellectual disabilities were interviewed. All participants work within the same organization for people with intellectual disabilities in the Eastern part of the Netherlands.

Ethical considerations

The study was conducted according to good scientific inquiry guidelines and ethical approval was obtained from a university ethics committee.

Findings

Most restraints of freedom were found to be centered around the basic elements in the life of the client, such as eating, drinking and sleeping. In justifying these restraints, support staff said that it was

necessary to give clarity in what clients are supposed to do, to structure their life and to keep them from danger.

Discussion

In the justification of restraints of freedom two ethical viewpoints, a principle-guided approach and an ethics of care approach, are opposing one other. Here, the self-determination theory can be helpful, while it combines the autonomy of the client, relatedness to others and the client's competence. Conclusion: Despite the reasonable grounds support staff gave for restraining, it raises the question whether restraints of freedom are always in the interest of the client.

Introduction

In the care of people with intellectual disability (ID), current emphasis lies on supporting and empowering clients to live their own lives. Their wishes, needs and rights are to be taken seriously. People with ID need to be seen as full participants in society and have to be treated as such. In this respect the United Nations have declared that everyone is entitled to all the rights and freedoms without distinction of any kind. Article 1 of the UN-convention on disabilities, states that 'the full an equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities is to be promoted' (United Nations, 2006). Reported disability prevalence rates from around the world vary dramatically, for example from under 1% in Kenya and Bangladesh to 20% in New Zealand (Mont, 2007). In Europe people with intellectual disabilities make up about 1% of the total population, an estimated 3.5 million persons (Walsh, Kerr, Van Schrojenstein, & Lantman-De Valk, 2003). A high percentage of these individuals is living in institutions, where support staff take care of them. The task of the staff is to support, sustain and take care of people with ID in a methodical and supportive way. In the Netherlands 2/3 of these support staff have an intermediate vocational education and 1/3 have a higher vocational education (VGN, 2012). With regard to the assistance they provide, in the past decades there has been a shift in paradigm: the focus on caring for people with ID is moved towards supporting people with ID (Van Gennep, 1997). Self-determination for clients is, in this perspective, an important factor for improving the quality of life of people with ID (Buntinx & Schalock, 2010). A focus on self-determination implies that restraints on the freedom of people with ID should be decreased by support staff, and that the support staff should show a sensitive and responsible attitude towards their clients in this matter (Abma et al., 2006). Discouraging restraints of freedom is desirable because it gives room for the clients to exercise their self-determination.

In line with this aim of diminishing restraints of freedom the Care and Coercion bill (2015) has recently been adopted in The Netherlands. This bill makes involuntary restraints of the freedom of people with ID illegal, unless reasonable grounds are found to restrain. Involuntary restrain of freedom is only

permitted in case of serious disadvantage for the client or for others. The bill states that an ID in itself can never be a legitimate ground to restrain freedom. Only the conduct of the client with ID can lead to the use of 'involuntary care' (Bill Care and Coercion, 2015). In this respect, serious disadvantage to the client is described as the threat of marginalisation, neglect or injury to the client, the threat of aggressive behavior directed at the client himself or others or the threat of harm to personal development or to personal safety (Bill Care and Coercion, 2015). The bill lists five forms of care which can be described as involuntary care. Besides well-known restraints of freedom such as isolation and physical restraint, the last category (5) refers to restraints on the client arranging his or her own life, so that the client has to do or to stop doing something (Bill Care and Coercion, 2015). This includes, for example, daily restraints in the use of social media, in deciding what to eat or drink, where to go or restraints in sleeping time and waking time. They are commonly used in daily care and applied as collective measures to all the clients living in the same house or living group (Dörenberg, Embregts, Van Nieuwenhuijzen, & Frederiks, 2013). The new bill states that these 'daily' restraints of freedom should be discouraged because they are seen as forms of involuntary care. They are only allowed to be applied if there is the threat of serious disadvantage for the client or her surroundings and reasonable grounds are found to restrain. But what is meant by serious disadvantage and what can be considered as reasonable grounds to restrain, is not clear and is up to support staff themselves (Dörenberg & Frederiks, 2012) requiring "careful deliberation and transparency" (Bill Care and Coercion, Explanatory Memorandum, 2015). Therefore, discouraging restraints of freedom leads to a great challenge for support staff, especially in the case of clients with challenging behavior (Allen, MacDonald, Dunn, & Doyle, 1997; Hastings, 1997; Hastings & Remington, 1994). Support staff are often confronted with a conflict between giving freedom to the client and protecting the client, between professional loving care and intentional caregiving. This ongoing tension can lead to ethical challenges (Hem, Molewijk, & Pedersen, 2014), such as how to deal with a client who doesn't want to take a shower once a week? Does the client neglect himself and can this be considered as a serious threat to the client? Do we need to force this client to take a shower or is it better to leave him alone

and encourage him to change his behavior by using other strategies?

Research on these daily restraints of freedom described in category 5 of the Care and Coercion Act is relatively scarce (Heyvaert, Saenen, Maes, & Onghena, 2014). Whereas *well-known* forms of restraints of freedom such as fixation and seclusion have been extensively investigated, less attention has been paid to research on *daily* restraints (Widdershoven, 2003). This study therefore focuses on the nature and justification of the use of daily restraints of freedom by support staff in order to get new input into the current discussion on restraints of freedom and good care of clients with moderate ID. Part 1 of this study concentrates on the description of these daily restraints. The question is raised of what support staff actually consider as restraint of freedom? What daily restraints do support staff see in their work? In Part 2 of this considers how daily restraints are justified. The Care and Coercion bill states that even daily restraints of freedom are categorized as restraining for clients with ID and is are illegal unless reasonable grounds are found to restrain. Restraint of freedom is only permitted in situations where it would prevent serious disadvantage to the client or others. In this section the focus is on the reasons support staff give for category 5 restraints of freedom (freedom to arrange the client's own life). How do support staff deal with restraints of freedom and how do they justify these restraints? Do they tend to emphasize the need to give the client freedom or are they more inclined to speak of the need to protect clients?

Methods

Participants

In the second half of 2014 15 support staff within a care organization for people with ID in the Eastern part of the Netherlands, were interviewed. All staff members mainly support clients with moderate ID (IQ 35-50) and four of them also support a few clients with mild ID (IQ 50-70). The clients were selected based on information in their clinical file with respect to their cognitive functioning.

Support staff working at all seven locations within one organization were interviewed (Verschuren & Doorewaard, 2010), including 8 (53%) staff members who work with people with moderate ID living at a residential facility, and 7 (47%) support staff working with clients with moderate or mild ID who are more integrated into society.

Table 1 *Demographic characteristics of support staff*

Characteristics	Subcategories	Count
Sex	Female	13
	Male	2
Age	<20	0
	20–30	3
	30–40	1
	40–50	6
	>50	5
Employment experience	<5	0
	5–10	3
	10–15	2
	15–20	2
	20–25	1
	25–30	4
	>30	3

Procedure

In this study data were collected by semi-structured interviews. Eight teams of support staff at seven locations were approached to cooperate with the research project. Support staff were provided with an information letter describing the background of this study, stating that the interviews did not emphasise fixing, separation or isolation of clients, but were specific to all other forms of daily restraints of freedom. In addition, in this letter it was ensured that all information given by the respondents would be made anonymous and treated confidentially and that support staff were given the opportunity to end the interview at any moment. Each team was asked whether two support staff would be willing to be interviewed. All teams agreed with this request, except one team which could

only bring in one participant. Support staff gave informed consent by signing the consent form paper just before the interview started. All the interviews were recorded on tape with consent of the support staff and afterwards literally transcribed. The psychological ethical commission of Tilburg University has granted permission for this research project (EC-2014.26).

Instrument

The interview topics and questions were described in an interview guide. Aim of the guide was to examine restraints used and the way support staff justified this use. The interview guide was piloted with two staff members of clients with moderate ID. Based on this pilot, a few changes were made in the formulation of the interview questions, with respect to clarity and uniformity. First, support staff were asked to define the term restraint of freedom, to determine whether they were using the term in the same manner. They were then asked to describe which daily restraints they see in their work. They were asked to describe all types of restraints of freedom, except fixing, separation or isolation of clients. Secondly, support staff were asked to describe how they deal with the application of restraints of freedom. How do they cope with these measures? For this, support staff were invited to relate their reasoning (justification) and moral attitude to the application of restraints of freedom.

Analysis

The first step was to transcribe the 15 interviews. The raw material was inductively coded using Atlas-ti software (Strauss & Corbin, 1998). Using open coding, a total of 99 codes were ascribed. Some of the codes were generated on the basis of interview questions, other codes were generated on the basis of the data itself. Codes connected by content were grouped. On the basis of these grouped codes, 5 categories were made. Three other researchers, within the same research team, checked this list of codes and categories for comprehensibility, congruence and internal consistency. From the 15

interviews, 3 were also systematically coded by one other fellow researcher (20%). The coding of these three interviews was found to have an agreement level of 89%.

Results

The main outcome of the study was that support staff justified restraints in different domains of the life of clients by emphasizing the necessity to offer clients clarity, structure and safety.

The outcomes of part 1 and 2 of this study are described in table 2. This table shows how support staff define the term restraint of freedom and in which daily domains restraints actually take place (Part 1). The table also includes ways in which support staff deal with restraints of freedom and how they justify and moralize them (Part 2).

Table 2 *Appearance and justification of restraints of freedom*

Definition, domains, reasons
Part 1
Definition of restraints of freedom
Deciding for the client
Constrict freedom of choice of the client
Domains of restraints of freedom
Eating and drinking
Daily structure
Bedtimes
Means of communication
Relations Hygiene
Part 2
Dealing with restraints of freedom
Communicate with the client
Know the client
Nudge the client
Keep distance from the client
Confront the client
Hide restraint of freedom

Reason for restraint
Client needs clarity (no overview consequences)
Client needs to stay in good health
Client needs to be prevented from danger
Client needs structure and rest
Reasoning due to organizational restraints

Moral attitude support staff
Doubt
Ambivalence

Definition of restraints of freedom

If daily restraints of freedom are a central theme, it is important to know how support staff define the term themselves. A prominent finding is that there is a great unanimity about a broad definition. All 15 staff members describe the term restraint of freedom as a way to decide for the client or to constrict his or her freedom of choice. This determining or constricting is visible in all aspects of the lives of clients. As one staff member states: “Restraints of freedom are connected to all things in daily life; other people, like parents and staff are constantly deciding for the client.”

Domains of restraints of freedom

Support staff were asked to describe all kinds of daily restraint of freedom that they see in their work. Results show us that restraint falls into different domains (1. eating and drinking 2. daily structure 3. bedtimes 4. means of communication 5. relations 6. hygiene). The restraints of freedom are listed in order of their frequency of appearance.

Eating and drinking

The restraints most mentioned by support staff referred to the eating and drinking of the client. Staff decide what clients eat, how much they may eat and the time of eating. Almost all of the eating and drinking by clients is regulated by support staff. This includes breakfast, lunch and dinner as well as snacks between meals.

As a staff member stated:

"So I decide what someone gets on his sandwich. Sometimes we prepare the sandwich the evening before, after we have asked what kind of sandwich they prefer. But you know, maybe they prefer something else in the morning instead of the sandwich made with cheese the evening before. Well, that is not possible. End of discussion. You get what you have chosen earlier."

Daily structure

In this domain, a variety of restraints related to the obligatory day structure were recorded. The restraints mentioned related to forcing clients to go to daily activities such as working in the garden or textile factory, and also to joining in with common activities. An example mentioned by a staff member was:

"The client didn't want to get out of his bed and for that reason we showed a firm attitude. We said to him 'you must listen, you have to go out of your bed, we don't want to have the same situation as yesterday'. My colleague and I helped him out of bed, put him on a chair and washed him. All of this very quickly because, of course, he didn't cooperate. He didn't hit us, but he wrestled with his hands and said 'no, I don't want to go'."

Bedtimes

Restraining also applies to the time clients want to go to bed in the evening or get out of bed in the morning. Clients are obliged to go to their own room, mostly around 9.00 or 9. 30 a.m., so that the support staff can do their work within the available time. The next morning the client has to be prepared for his or her daily work. As a staff member stated:

"At ten o'clock my shift is done. So at that time everything must be done and prepared for the next morning. And all the clients need to be in bed. In the morning clients also have to get up at a certain time, mostly 7.30 a.m. They have to be prepared for their daily activities. Only in special cases are exceptions made, for instance when a client is ill or extremely tired."

Means of communication

Most of the restraining was found to be concentrated on the basic needs and wishes of the clients, but restraints were also applied to means of communication such as the use of laptops, mobile phones or iPads. Restrictions were made in the time of use, e.g. no use of laptops in the evening, as well in the internet sites that clients were allowed to visit. One staff member described an example:

"We have a young man in this house who goes to bed at 9.30 p.m. He certainly needs his sleep, but when we as staff are out of his room, he takes his tablet out and uses it for a long time. The next morning he is extremely tired. Along with his parents we came to the conclusion that he has to hand his tablet over to us in the evening before he goes to his bedroom"

Relations

Relational restraints were only mentioned by the 7 support staff working with clients who are more integrated into society. Staff tended to restrain clients in their relations when they felt that was in the best interest of their clients to discourage certain contacts. Support staff determined, for instance, which people were welcome to visit their clients and which people were not allowed. Support staff decided in this way who was allowed to enter the house where the client lives and who may not. They also intervened in relationships between clients to keep their own clients from harm or from doing harm to others. An example was given in which support staff preferred to have more control over a relationship:

"A boyfriend of our client had more expectations from the relationship than she had herself. She looked for a coffee friend, but he wanted more. As staff we said that it was better that she didn't go to his place anymore and only let him come to her own house. In this way we always kept an eye on what happened between them".

Hygiene

Support staff also report restraints in personal hygiene. This refers to stimulating or forcing unwilling clients to take a shower, to go to the bathroom or to brush their teeth. Support staff consider it their duty to take care of the personal hygiene of the client. Therefore their presence in the bathroom is sometimes needed. An example stated by a staff member:

"We have one client, who has to take a shower every day. We join him into the bathroom till he gets undressed and we wait until he has completely washed himself. Then we leave the bathroom. However, this is uncomfortable for him. He doesn't think it is necessary. He also thinks he can wash with a face cloth."

Dealing with restraint of freedom

The way support staff deal with restraint of freedom is described in the following section. Here they examine different ways of getting restraints methods accepted, from communicating with the client in order to get the restraint of freedom more accepted to confronting the client with his own attitude.

Communicate with the client

Support staff state that starting a process of communication with the client can lead to better acceptance or even a decrease of daily restraint of freedom. They are willing to explain the situation to the clients, telling their clients why it is good for them that there are restrictions. Or they offer clients a choice between various restraints of freedom. They also just listen to the complaints of the clients to show respect for their feelings. With regard to offering choices, a staff member explained:

"In earlier times, the client only was allowed to eat a sandwich with a sweet filling after he had eaten a sandwich with meat or cheese. And it is just a few years ago that only coffee was offered instead of giving the client the possibility to choose between lemonade, coffee, tea or water… You have to give clients the opportunity to choose and then you see that they are able to make a lot of choices for themselves."

Know the client

In this respect a good relation with the client is of great value, according to support staff. Knowledge of the client and having a bond with him or her can result in a decrease of restraint of freedom. Support staff are daring to experiment more with well-known clients. They are more willing to relax fixed daily structures and give the clients more space because they trust their clients due to their bond. A staff member stated*:*

"There is a client who I have already known for 30 years. I have been through a lot with him. There is mutual trust between us and this means that I have to restrain him less. When he wants to do something special, I know if he can manage it. With new clients I don't have this bond and there I have to be more restrictive in the beginning."

Nudge the client

In situations where there seems no alternative to the restraint, support staff sometimes use the method of nudging. Nudging is a way to lead clients to a certain goal. For the clients, however, there is always a way out. Clients are encouraged to conduct the supposed action, but there is no use of coercion. Nudging is used when clients have to go to their bedrooms but don't feel like it. An example by a staff member:

"I introduce the idea that they have to go to their bedrooms. I clean up, I switch off some lights. I am preparing them so that they feel 'it is time'."

Keep a distance from the client

Another way of dealing with restraint of freedom is remaining at a distance from the situation. Support staff tell their clients what needs to be done, but they don't push them to do it, they remain at a certain distance. An example that a staff member mentioned: "To the client I say: 'you are going to take a shower right now and in about fifteen minutes I will see you at the table'. And then I walk away from the bathroom. This works."

Confront the client

In other situations support staff choose confrontation with their clients. They want to make a point clear and they continue with their action until the client has done what they want him or her to do. As one staff member stated:

"The same clients always want to stay in bed in the morning. But then you tell them about their responsibilities. They are waiting for you at work. And, I have come to work, so you have to go to your work too.' Sometimes they grumble about it. This grumbling is part of their morning ritual. But at a certain point they get out of their beds."

Hide restraint of freedom

Camouflaging the daily restraint of freedom is another method used by support staff to deal with restraining. Clients who want to eat more than is supposed to be good for them, get a small portion twice or the meal is spread out on the plate in such a way that the amount of food seems to be more. Another example of camouflaging by a staff member was described as: "The Dutch soccer team had to play a game late in the evening. Too late for the client, because it was after his regular bedtime. But he wanted to see the match so much. So I switched the television on around six o' clock in the evening. There was another soccer game going on. The client watched the game and I didn't say to him: this is not the Dutch team playing, it is Belgium. Actually, I was telling a lie. But it was because I felt sorry for him because he couldn't watch the right game."

Reasoning

Support staff enumerate many arguments for restraining their clients. In the following section five codes based on reasoning are listed.

Client needs clarity

The main reason mentioned by support staff is the necessity to provide the client clarity by restraining. Support staff state that clients cannot foresee the consequences of all their actions. They have to give clients clarity in what they are supposed to do and tell them what consequences their actions can have upon them and others. Support staff have the opinion that such supporting method can give clients a feeling of safety. For example, with regard to eating one staff member explained:

"Clients are not able to choose their own meals. The first client says: I don't feel like that, I don't want to eat it. A second client takes four portions of meat. And the third client wants nothing at all. They need clarity, they just cannot do it by themselves."

Client needs to stay in good health

Another important main reason for restraining focuses on the health of the client. Some clients habitually eat too much, more than is good for their health. They need to be restrained in eating and drinking, otherwise they become too overweight:

"My client is at risk of becoming really far too overweight, which is quite unacceptable. At a certain point she will not be able to move anymore and she is also a diabetic."

Client needs to be kept out of danger

This aspect emphasises the importance of keeping clients out of dangerous situations. Clients can cause danger to themselves and to others. According to support staff, this risk emerges, for instance, when clients with ID have or want to have sexual relationships. Clients are very vulnerable in this respect according to support staff. The danger some support staff consider in the client getting into a (sexual) relationship focuses on changes in the clients' behavior. An example from one staff member:

"You don't keep a client from having a relationship, but for a large number of clients having a relationship is quite unacceptable. Actually, allowing a relationship to happen is the worst thing to

do…. Clients change their behavior, aggressive behavior increases or behavior that is difficult to interpret appears. Emotions. A lot of things come out in an explosion."

Client needs structure and rest

Furthermore, clients need structure and rest for their own well-being. According to support staff they are unable to maintain a daily structure themselves. This structure focuses on the time clients have to go to their daily activities and on fixed bed times. As one staff member said:

"We have quite a lot of clients here who are very sensitive to stimuli. This means that they are exhausted by around eight or nine o'clock in the evening. They need to deal with these stimuli, so a great number of clients go to bed early."

Reasoning due to organizational restraints

All of the above reasons refer to the client as an individual, who needs to be helped in daily activities and needs daily support. However, there are also reasons for restraining that are not client-related, but are related to organizational boundaries. Support staff have reduced possibilities to give good care due to limited working time and staff shortage. A lack of support staff in the night, when there are only a few night workers, can lead to the following situation, as one staff member described:

"Our client is awake at 5.00 A.M. She screams and shouts because she wants to get out of her bed. But we start at 7.30 A.M., so she has to adjust herself to the organization. The organization doesn't adjust to her."

Moral attitude

Although support staff report reasonable grounds for restraint, they are not always certain of their own choice to restrain. Morally, they sometimes raise questions about their own behavior. Doubt and moral ambivalence in the minds of some support staff are sometimes intrinsic to applying restraints of freedom.

Doubt

Feelings of doubt can increase over time. Support staff sometimes ask themselves if they have done the right thing, as in the following description by one staff member:

"I experience dilemmas all the time. I think that I have done the right thing, but I always feel doubt. You never know... What is the right thing to do?"

Ambivalence

These doubtful feelings can lead to moral ambivalence. Some support staff sometimes find it difficult to find a balance between supporting their clients and prohibiting them doing things. For instance the following staff member, who emphasizes the ambivalence between personal feelings and rational decision making:

"It really affects me when I work with somebody who shows resistance. But I keep in mind that it is in his own interest."

Discussion

The goal of this study was to get insight into the nature (part 1) and justification (part 2) by support staff of their use of restraints which effect the client's freedom to arrange his own life. The aim of the study was furthermore to get new input in the current discussion on restraints of freedom in clients with moderate ID. We found that most restraints of freedom concentrate on basic elements in the life of the client, such as eating, drinking and sleeping. Other restraints focus on the social life and relationships of the client. Support staff mention different, in their opinion, reasonable grounds when justifying the use of restraints. They emphasize the need to give clarity in what clients are supposed to do, to give them the necessary rest, to structure their life and to keep them from danger. Support staff constantly point out that clients with ID are vulnerable human beings. 'Serious disadvantage' for clients is to be excepted when clients are not restrained in certain situations. According to support

staff, some clients might, without restraint, for example, eat too much, get too little sleep, visit violent or sex-orientated websites, get in touch with 'wrong friends', and neglect their personal hygiene. To keep them from these dangers, support staff want to show a responsible attitude toward their clients. Staff are, in principle, willing to give their clients freedom, but they are convinced that clients with ID cannot always handle this freedom. According to support staff, the nature of their client's disability is that they cannot oversee their own actions.

Methodological limitations of this study should be noted. First, support staff from within only one care organization, were interviewed. Organizations have their own specific culture regarding restraining however; interviewing support staff from other care organizations might lead to different results. Second, in the interviews we did not inform support staff about possible restraints used. Since staff were asked to formulate restraints themselves, it is possible that some restraining is not mentioned based on social desirability. This strength of this study is related to the valorisation of the results. Outcomes of this empirical study can be used in education programs for support staff and are relevant for daily practice.

In discussion of the justification of restraints of freedom there are, two ethical viewpoints opposing one other. On the one hand there is the principle guiding the approach seen in the Care and Coercion bill. In the bill it is stated that, in principle, every involuntary restraint of freedom is illegal. The principle of self-determination for every human being also being applied to people with ID leads in this direction. The autonomy of the client is the point of departure in this principle-guided view. From an ethical point of view, Beauchamp and Childress (2014) emphasize this focus on client's autonomy where the client has the right to make her own decisions without interference from others. Self-determination is also an important factor in improvement of the quality of life (Buntinx & Schalock, 2010; Claes, Van Hove, Van Loon, Vandevelde, & Schalock, 2009). On the other hand, in line with the view of support staff, care ethicists emphasise the moral responsibility of support staff and the relation between client and the caregiver who listens carefully (Van den Hooff & Goossensens, 2014): 'An ethics of care sees moral questions more in terms of responsibilities than of rights' (Verkerk, 2001). Clients

with ID are, in the view of care ethicists, vulnerable people. Not the self-determination of the client, but the vulnerability of the client should be the point of departure (Van Heijst, 2011). Restraint of freedom, in this viewpoint, can be justified as a way to restore the autonomy of the client. The danger of abandonment of clients with ID is a greater risk than the danger of interference (Verkerk, 2001). This is in line with the attitude of support staff in this study. They are convinced that they restrain in the interest of the people whom they care for (Cullity, 2007; Stoljar, 2007). Staff experience the application of restraints of freedom in specific situations as justified, but they also feel the moral weight of applying the restraints in practice (Fish & Culshaw, 2005).

When considering both ethical orientations, some risks can be pointed out. With regard to the principle-guided approach, there is a risk that the focus on self-determination neglects the active relationship between the client and support staff. A focus on self-determination should not mean that clients are left alone (Verkerk, 2001), for example leaving a client in a depressive mood in her own room for a few days because she doesn't want to join in with common activities. In the interaction between clients and support staff, clients must be helped and sustained by staff to lead their own lives. In self-determination theory, Ryan and Deci (2000) point out that, besides the autonomy of the client, relatedness to others and the client's competence are crucial elements. Clients who interact with attentive and sensitive support staff, feel more respected and accepted (Roeleveld, Embregts, Hendriks, Van den Bogaard, & Verbrugge, 2012). A safe, warm environment can give clients the feeling that they are taken seriously and can increase their autonomy and competence. With regard to the care ethics approach, there is the serious risk that the interest of staff or the organization is leading instead of the interest of the client. For a staff member it can be an easy way to forbid clients to do certain things e.g. using social media, instead of giving them controlled space to do these things. If the focus is not on the self-determination of clients, but on the relational aspect between client and staff, the hierarchical element in the client – staff relation can be underestimated. Staff members are the ones who are in the position to make decisions for clients. Relatedness between clients and staff should therefore always be connected with client's autonomy and competence. This connection

between autonomy, relatedness and competence can function as a guarantee that the restraining really is in the interest of the client. Restraining in the interest of the staff member or organization, for example maintaining a limited number of support staff and limited working times for staff to keep the costs low, is in this view morally unacceptable. Care ethics point to this risk that the hierarchical relation between support staff and clients can be misused. They plead for coaching of professional loving care and developed material for support staff with the emphasis on a trusting relationship between staff and clients (Van Heijst, 2009, 2011; Embregts, Hermsen, & Taminiau, 2015). The focus in this professional loving care program is on seeing the client as a person. Every person needs attention, trust and also a feeling of freedom of choice. By building up a trusting relationship with space for the client's own decision making, staff do justice to their clients.

All in all, the view of the clients regarding restraining is, of great value. How do they experience the restraints in arranging their own lives for themselves? Further research is necessary to explore the perception and assessment of daily restraints of freedom by clients themselves. Therefore, we are conducting a follow-up of this study in which we are examining the perspectives of clients themselves on this matter.

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Appendix 1

Restraints of freedom applied to clients with ID according to support staff

Category	Subcategory	Codes
Definition of restraints of freedom	Decide for another	Restraining means deciding for another
		Restraining means that the client wants something that is not allowed
		Restraining means deciding for another by measures defined by the law
		Restraining means constricting the freedom of choice of another
	Constrict the freedom of choice	Restraining means that the other is out of control
		Restraining means stimulating the vulnerability of the other
Domains of restraints of freedom	Eating and drinking	Client does not choose his/her own food/drinks
		Time for eating is determined
		Client has to wait for dinner
		Client has to take breakfast in own room
	Bedtimes	Client has to go to bed at a fixed time
		Staff member determines the time that client gets up
	Daily structure	Client has to join activities
		Client has to wait for support from staff
		Client is forced to go to daily activities
		Client has to wear clothing selected by staff
		Client has to wind up ritual in the morning
		Client is not allowed to join walking tour
		Client is obliged to spend a part of the evening in living room

		Client has to cycle on home trainer
		Client has to be home on time
		Client has to hand in cigarette lighter
	Relations	Staff member applies restraints to amorous relations of clients
		Staff member strongly advises client to tell about amorous relationship to own brother
		Staff member ends client's relationship by forcing her to move to another house
	Means of communication	Restraints in the use of social media
		Restraints in the use of internet
	Hygiene	Client is forced to take a shower
		Client is restricted in time to take a shower
		Client is only allowed to go to the toilet at a fixed time
		Client is assigned to go to the toilet
	Other	Client is not free in choice of wallpaper
		Client does not have own key
		Client is not free in choosing destination for holiday
		Client is not free in spending pocket money
Dealing with restraints of freedom	Communicate with the client	Listen to what the client has to say
		Offer clients choices
		Explain the situation to the client
		Make a joke as form of communication
		Consider before applying restraints
		Start a dialogue with the client
		Discuss with client
		Deliberation with colleagues
		Decision making with team
	Know the client	Knowledge of client is helpful in the process of caring
		Bond with client is helpful in the process of caring
	Nudge the client	Make the bedroom an attractive place to be

		Make the goal attractive
	Keep distance from the client	Mention consequences of actions of the client and then leave the area
		Not confront the client
		Act if you do not see the client
	Confront the client	Point out client's own responsibility
		Let client feel the pain of own decision
		Staff members have to act firmly
		Write down the agreement with client
		Point out the agreement with client
	Hide restraint of freedom	Spread out the food on the plate, so amount of food seems more
		Lie to the client about soccer game on television
Reasoning	Client needs clarity	Clients do not foresee the consequences of their own actions
		Clients need clarity in decision making
		Clients need mother figure
		Clients need clarity in traffic situations
	Client needs to stay in good health	Clients need to be restrained in eating and drinking
		Clients need to go to bed on time to stay fit
		Clients need to be prevented from having bad hygiene
	Client needs to be kept out of danger	Prevent clients going into surroundings that may be dangerous
		Clients are vulnerable to sexual abuse or are instigators of abuse themselves
	Client needs structure and rest	Clients need rest
		Clients need structure
	Reasoning due to organizational restraints	Restraints in working hours of staff
		Hospitalization of clients and staff

		Cramped living conditions of clients can lead to restraints
Morality	Doubt own choices	'Am I doing the right thing?' 'After restraining, there is always doubt' 'Am I allowed to decide this?' 'On which side do I stand?' 'By applying restraints, we mask our own uncertainties'
	Ambivalence	Feel annoyed about restraints, but necessary for client Choice has been made to restrain, but choice does not feel completely right Emotionally, restraining feels terrible Own norms and values of staff are all right, but staff have to release them if necessary Search between supporting and prohibiting Restraining as well as positive as negative Difficult to find balance Difficult to release instead of to protect

Chapter 3

How do people with moderate intellectual disability evaluate restrictions in daily care?

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Abstract

Introduction

One of the general articles of the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) focuses on the right of freedom to make one's own choices and being aware of the importance for persons with disabilities to obtain independence. People with intellectual disability (ID) are, to a greater or lesser degree, dependent on significant others, such as support staff with respect to decision making. For that reason, the UNCRPD also stresses the relevance of supportive decision making, which should be stimulated by service policies. However, support staff may find it necessary to restrict people with ID to make their own choices, for example to prevent them from harm. Since restrictions should be applied in the interest of people with ID, it is essential to examine their own perception. In this study, we have examined how people with moderate ID themselves perceive and evaluate restrictions in daily care, using a qualitative methodology.

Method

Based on an extensive pilot study, we conducted interviews being close in time and place in which possible restrictions might occur. Additionally, we applied triangulation of sources. After conducting interviews with eight persons with a moderate ID, we examined their clinical files and interviewed their key workers. Qualitative analysis was carried out by two researchers, using an inductive, thematic approach.

Results

Results demonstrate communality between the participating people with ID and their key workers in perception and evaluation of restrictions, in people with ID tending to comply with the applied restrictions. When the participants with ID and their key workers differ in their evaluation of applied restrictions, this appears a value based dissensus. Conclusion: To ensure that restrictions are applied in the best interest of people with ID, it is essential that staff are attentive to the wishes of people with

ID, which might be based on different values. By asking people with ID about their experiences and views of the restrictions imposed on them, we hope to contribute to an ongoing and open dialogue to inform the planning and delivery of services for people with ID based on 'best interest' principles.

Introduction

In the care for people with intellectual disability (ID), a paradigm shift has taken place in the last few decades; the focus on caring for people with ID has changed to a focus on supporting and empowering them to arrange their own lives (Tideman, & Svensson, 2015; Van Gennep, 1997). In line with this paradigm shift, a general article of the Disability Convention focuses on the right of freedom for people with physical and intellectual disabilities to make their own choices (United Nations Convention on the Rights of Persons with Disabilities (UN, 2006, Article 3.1). People with ID are, to a greater or lesser degree, dependent on significant others, such as family members and/or support staff with respect to decision-making (Antaki, Finlay, Walton, & Pate, 2008; Van Asselt, Embregts, & Hendriks, 2015). For that reason, the UNCRPD stresses the relevance of supportive decision making (UN, 2006, Article 12.3; Williams et al., 2015), which should be stimulated by service policies.

Support staff play an important role in the daily life of people with ID. On the one hand, it is their responsibility to provide people with ID space and freedom to make their own choices, on the other hand, it is also their task to protect people with ID from harm, as a consequence of which they may need to restrict them in making their own choices (Verkerk, 2001). Hence, applying restrictions can be part of providing good care, but only insofar as these restrictions are in the interest of people with ID and are decided upon in dialogue with them (Van Dartel, 2007; Abma et al., 2006).

Restrictions in care can be described from several perspectives, e.g., from a political, sociological, legal or ethical perspective (e.g. Arvidsson, Granlund, & Thyberg, 2014; King, Edwards, Correa-Velez, Darracott, & Fordyce, 2016; Kultgen, 2014). In this study, we follow the definition proposed in Dutch legalization regarding care for people with ID and people with a psychogeriatric disorder (Wetsvoorstel Zorg en Dwang, 2017).

This bill lists nine categories of involuntary care, among which well-known restrictions and restraints such as isolation and physical restraint. This study focuses on a special category (Article 2.1.h) in which restrictions are defined as measures “to arrange the client’s life in such a way that the client

has to do or to stop something" (Wetsvoorstel Zorg en Dwang, 2017, article 2.1.h). This includes, for example, daily restrictions in the use of social media or restrictions in bedtimes. Such restrictions are commonly used in daily care for service users and applied as collective care to all the clients living in the same house or living group (Dörenberg, Embregts, Van Nieuwenhuijzen, & Frederiks, 2013). In case people with ID show protest against these restrictions, these are seen as involuntary care according to the bill. Only in case of serious disadvantage for the person with ID or others, involuntary care is permitted. As stated in the bill, an intellectual disability in itself can never be a legitimate ground to restrict people's freedom. Only the conduct of the person with ID can lead to the use of 'involuntary care'.

In an earlier study conducted amongst support staff, we found that support staff applied restrictions thus defined in different domains of daily life, i.e., eating and drinking, hygiene, social contacts, means of communication and bedtimes. Examples of restrictions thus defined are diet rules to protect people with ID from obesity, or restrictions regarding use of social media to protect them from unwanted or predatory contacts. From their perspective, support staff applied these restrictions to provide safety, structure and clarity for people with moderate ID, although they also experienced moral doubt regarding the application of restrictions in general, and more specific regarding the extent to which restrictions are in the best interests of people with ID (Van der Meulen, Hermsen, & Embregts, 2016).

Since restrictions should be applied in dialogue with and in the interest of people with ID (Dörenberg, Embregts, Van Nieuwenhuijzen, & Frederiks, 2013), it is essential to examine how people with ID themselves perceive the applied restrictions (UN Chronicle, 2004). Exploring their perception and evaluation of restrictions may deepen our understanding of the extent to which people with ID agree or disagree with applied restrictions. Moreover, it may illuminate whether the applied restrictions can be considered in the best interest of service users. Most research in this area concentrates on the perception and evaluation of restrictions by people with mild ID (e.g., Heyvaert,

Saenen, Maes, & Onghena, 2014b; Negenman, Embregts, De Bakker, Van Nieuwenhuijzen, & Frederiks, 2014; NIVEL, 2013). These studies indicate that people with mild ID do not always agree with restrictions in daily care. Research that includes the perspective of people with severe ID via family members or support staff shows that they believe that people with severe ID have few experiences of restrictions as their intellectual disability causes them to be unaware of the applied restrictions (Embregts et al., 2017). Studies examining the perception of people with moderate ID on restrictions in daily life are scarce however. Therefore, we have conducted a qualitative study, addressing the research question: how do people with moderate ID perceive and evaluate restrictions applied to them in daily care and to what extent do they agree with these restrictions? Due to the cognitive and communicative abilities of people with moderate ID, we were not able to replicate the methods used to collect qualitative data on the perception of restrictions amongst people with mild ID. Based on an extensive pilot study we developed a tailored method to include the perspective of people with moderate ID, on which we will report in this paper.

Method

Participants

After ethical approval by the Ethics Committee of Tilburg University (EC-2015-14), participants were recruited via a care organization for people with ID in the Netherlands. The first inclusion criterion for participation was the level of intelligence, i.e., moderate intellectual disability (IQ 35/40 – 50/55, American Psychiatric Association 1994). Two health psychologists from the care organization selected all service users with this classification in their clinical files. To exclude people with profound intellectual disability from this study, the ability to verbally communicate in an understandable way was set as a second inclusion criterion (American Psychiatric Association, 2013). This ability and an additional verification for not having severe ID was also assessed by the two health care psychologists, based on personal contacts with the service users.

Participants were randomly selected from a pool of 25 people. As an additional check for not including people with mild ID, these participants carried out an IQ test (Wechsler Adult Intelligence Scale 2012) conducted by a health psychologist with no affiliation to this study (Table 1).

Table 1 *Demografic characteristics clients*

Client	Gender	Age	IQ	Setting	Number of years in care organization
1	F	60	<55	Residential	53
2	M	35	<55	Residential	14
3	F	33	<55	Residential	15
4	F	54	<55	Residential	31
5	F	62	<55	Residential	4
6	M	47	<55	Family home	15
7	M	54	<55	Family home	20
8	M	46	<55	Residential	0.2

According to guidelines of the Ethics Committee of Tilburg University, permission was gained from their legal representatives to allow them to participate in this study; this was done by sending the representatives an information and consent letter explaining the background of this research. In the letter, it was explained that all information given by the participants would be made anonymous and treated confidentially and that participants were given the opportunity to end the interview at any moment without providing a reason and without negative consequences. The consent letter also stated that the data would be stored for ten years, according to the guidelines of Tilburg University. Next, the researcher gave the representatives of the people with ID the opportunity to make inquiries about the study by phone or mail. They were given at least two weeks to decide whether or not they would give

the client permission to take part in the study. The people with ID that were given permission to take part were informed about the study by their support staff and personally asked for consent to participate, to which all people with ID agreed. In total, eight people with moderate ID participated in the study.

To gain as much information as possible about the perception of restrictions by people with moderate ID, their support staff were also interviewed. All key workers of the eight participants with ID received an information and consent letter informing them about the study and asking for consent to participate in an interview. In line with the legal representatives of participating people with moderate ID, they were also given two weeks to consider their cooperation; the researcher (APM) phoned them during this period to check whether the aim of the study was clear to them. They all gave their written consent.

Procedure

Because of the paucity of studies in which people with moderate ID are interviewed, first a reliable method to collect data was developed. In a pilot study, we conducted an interview based on five domains of daily life: 1) bedtimes, 2) hygiene, 3) eating, 4) social contacts and 5) means of communications (Van der Meulen, Hermsen, & Embregts, 2016). The day was visualized by drawing a simple continuum starting with the morning and ending with the evening. This continuum was used to guide the people with ID through the different life domains and ask them for possible restrictions in each of these domains. In addition, pictures were used representing the particular life domains. However, participants tended to agree to all possible restrictions. Therefore it remained unclear whether they really understood the questions and to what extent they had provided socially desirable answers.

To promote the reliability and internal validity of our study, we therefore adapted our method of data collection. Firstly, instead of conducting a single interview, we interviewed the client during

three specific times a day (in the morning 8.00 – 8.45 A.M., at the beginning of the evening 6.30 – 7.15 P.M., and later in the evening 8.15 – 8.45 P.M.) during which restrictions in a particular domain of daily life may occur, such as restrictions in hygiene in the morning, in receiving social visits at the beginning of the evening and at bedtime later in the evening. In addition, these interviews were administered in or nearby the setting these restrictions might occur (see Table 2). In this way, we were not only close in time and place, but we also included the context of the living environment of the person with ID. For example, the interviewer asked the client if he could see the clients' bathroom at nine o'clock in the morning, asking where and how the client washed him or herself this morning, knowing that the client washes him- or herself every morning. Subsequently, the interviewer asked whether there were limitations or restrictions in using the bathroom. Finally, the interviewer asked participants with ID how they evaluated the self-mentioned daily restrictions by inviting them to choose between three possibilities related to each of the five domains: 'good', ' could be better', 'not good'. The three possibilities were supported by pictures frequently used in the care organization: a picture with a thumb up ('good'), a thumb sideways ('could be better') and a thumb down ('not good'). In reaction to the client's choice, the interviewer (APM) further probed to clarify why the client chose the indicated response option. For instance, 'Can you tell me more about why you chose "could be better"'? Prior to conducting the interview, the interviewer did not obtain any information about the participants to limit bias in interpreting their accounts. All interviews were audio-recorded. The participants were offered the possibility of listening to the audio-recorded interviews, which was done by two participants.

Table 2 *Domain, time and location of interviews*

Domain of daily life	Time of interview	Location
Bedtimes	8:00 AM	Bedroom
	8:30 PM	Bedroom
Eating	8.30 AM	Living room
	6.30 PM	Living room
Hygiene	8:15 AM	Bathroom
Social contacts	7.00 PM	Bedroom
Means of communication	6.45 PM	Living Room
	8.15 PM	Bedroom

Secondly, we adapted the method of data collection by applying triangulation of sources in collecting information (Boland, Daly, & Staines, 2008). After conducting the interview with the person with ID, we systematically analyzed the clinical file of that person with respect to information regarding 1) possible applied daily restrictions and 2) the person's perception of these restrictions. The Ethics Committee of Tilburg University, the board of the care organization as well as the legal representatives provided consent to look at the files of the participants. We then interviewed the key worker of the person with ID regarding the restrictions applied. The interview with the key worker took place within two months of the interview with the person with ID. In line with the interviews with the people with ID, these interviews were based on the five aforementioned domains of daily life. First, key workers were asked what kind of restrictions were applied to the people with ID and subsequently, they were asked how people with ID perceived and experienced these restrictions according to their own opinion. Information from the clinical file of the person with ID regarding restrictions was mentioned by the interviewer when key workers did not mention this information themselves.

Analysis

Qualitative analysis of all interviews and clinical files was carried out by two researchers (APM, ET), using an inductive, thematic approach (Braun,& Clarke, 2006). The analysis started with the verbatim transcription of the interview with the person with ID, which was then coded inductively by both researchers independently. In case of disagreements, consensus was negotiated. Next, the clinical file of the person with ID was checked by the first author for information regarding daily restrictions. Subsequently, this information was coded by both researchers. Again, consensus was negotiated in case of disagreements. Finally, the interview with support staff was transcribed verbatim, and coded inductively by both researchers independently. Both researchers negotiated consensus in case of disagreements. All analyses were conducted supported by Atlas-Ti (Muhr, 2005).

After both researchers (APM, ET) completed two cases (participants 1 and 2), four researchers (APM, ET, PE and CH) explored the data and discussed the themes derived. This process was repeated after three additional cases (participants 3 to 5). At that point we concluded that the interviews with the latter participants showed the same findings. A possible explanation for these similar results was that all people with ID lived for an extended period of time (from four to 53 years) in a residential setting and in time might have become used to the institutional restrictions. In search of possible disconfirming or negative cases, we therefore added three cases (participant 6, 7 and 8): two with respect to another type of care setting within the same organization (i.e., people with ID living in a family-home instead of a residential setting) and one with respect to duration of residency in the same organization (i.e, a person with ID who lived in the care organization for only two months). These three cases were analyzed in the same way as the first five cases, and confirmed earlier findings. Therefore, we concluded that data-saturation was achieved (Guest, Bunce, & Johnson, 2006).

Results

In analyzing the data inductively, three major themes emerged: 1) communality between people with ID and support staff 2) mutual benefit and 3) disagreement by people with moderate ID.

Communality between people with ID and support staff

Table 3 lists the five categories in which daily care is provided, the restrictions within these categories the participants are aware of and whether participants agree or disagree with these restrictions. In addition, the table shows which restrictions are applied in these categories of daily life according to their clinical files and according to their key workers. Participants did not experience restrictions in the category social contacts or agreed with them. Participant 8 did not mention restrictions in any category at all.

Participants indicated to experience the restrictions to which they agree as part of their daily lives and do not challenge them. In case participants agree with the restrictions, this agreement is confirmed by their key workers. The following excerpts illustrate the communality between the person with ID and the key worker in perception and evaluation of diet restrictions, starting with a description from a key worker:

> Our client is motivated to stick to her diet. It is for her a nice guideline to watch her weight. She surely shows no resistance against her diet.
> (Key worker client 3)

The client herself reports:

> Client: Staff tell me that I am not allowed to eat too much. I have a special diet.
>
> Interviewer: What do you think of that?
>
> Client: I think it is all right. Every Friday I weigh myself on the scales. I do not like to get too fat.
>
> (Client 3)

Subsequently, in the clinical file of client 3 it is described that 'the client has a special diet preventing her from obesity'. The clinical file contains no notification of (dis)agreement from the client to this restriction.

The following example, restrictions regarding bedtimes, also demonstrates communality in evaluation between the person with ID and the key worker. The key worker describes the client's bedtime restrictions as part of the daily structure and in line with the client's wish:

> She [the client] asks for structure herself… At eight o'clock the television is turned off and clients get ready for bed. At half past eight she goes to bed. She needs that rest and it is okay for her.
>
> (Key worker client 4)

The client expressed agreement with the restriction in bedtimes:

> At half past eight I go to bed. As it starts to get dark I have to sleep. That's okay. I need my rest.
>
> (Client 4)

Subsequently, the report in the clinical file confirms this bedtime restriction in a very brief way, i.e., 'fixed bedtimes for client are necessary to provide rest and structure' (clinical file, client 4). (Dis)agreement from the client to the restriction is not described in the clinical file.

Table 3 *Perception of restrictions in daily care according to clients, clinical files and support staff (N = 8)*

Categories	Disagree with restrictions according to the client	Agree with restrictions according to the client	No restrictions according to client	Restrictions according to file	Restrictions according to support staff
1. Eating	Client 2, 7	Client 1, 3, 4, 5, 6	Client 8	Client 2, 3, 4, 5, 6, 7	Client 1, 2, 3, 4, 5, 6, 7
2. Hygiene	Client 1, 3	Client 4, 6	Client 2, 5, 7, 8		Client 1, 3, 4, 6
3. Social contacts		Client 2, 3, 4	Client 1, 5, 6, 7, 8		Client 1, 2, 3, 4
4. Means of communication	Client 2, 6	Client 3, 4, 5, 7	Client 1, 8	Client 2	Client 2, 3, 4, 5, 6, 7
5. Bedtimes	Client 1, 4, 7	Client 3, 5, 6		Client 4	Client 1, 3, 4, 5, 6, 7

Mutual benefit

Participants consider the applied restrictions to be beneficial for themselves and also for others like family members. The restrictions are believed to promote their own and others' well-being as well as the quality of their relation. Interviewees mention in this respect the following justifications namely a) promoting their own physical and mental health, e.g., restrictions regarding drinking and eating (*I am a diabetic, I have to be cautious with eating,* client 6) b) promoting their safety, e.g., restrictions in using a mobile phone to keep people with ID from doubtful contacts (*It is not allowed to have [mobile] contact with boys, for my own safety,* client 3) c) obtaining structure and rest, e.g., restrictions regarding fixed bedtimes (*I need my rest, so I go to bed at half past eight,* client 4) d) preventing others from inconvenience, e.g., restrictions in contact with family members (*My brother has other things to do, he*

has a busy life, so I better not phone him, client 2) e) dealing with organizational reasons, e.g., restrictions in duration of bathing time due to limited worktime of support staff (*Support staff also need to help others,* client 5).

In addition, data indicate that the justifications mentioned by people with moderate ID might be derived from justifications provided by significant others like family members. People with ID explicitly refer to these significant others in mentioning the justifications for the applied restrictions. This is shown in the next two interview fragments in which people with ID describe that the restrictions stem from their parents. People with ID seem to adopt these justifications. In the first fragment, the client justifies a restriction, originating from his mother, in the domain means of communication. The client experiences the limitation in phoning as a restriction, but does accept the restriction imposed by his mother:

> I may phone my mother once a week on Tuesday, but I may not phone my brothers. My brother B. has a very busy job... My other brother F. is also very busy with the children. Therefore, my mother has decided that R. [the client speaks of himself in third person] does not make any phone calls to them, unless their children are older or go their own way… or something like that... I like to phone him and I like to talk a lot... My brother B. himself does not phone me... But I cannot blame him for that, because he is very busy with his work, his children and with doing his shopping. And he also needs to play tennis. (Client 2)

The key worker of the client states that the reason why the client is restricted in calling his mother and is prohibited from calling his brothers stems indeed from the mother, but is also supported by support staff. According to the key worker:

> The client can rattle for an hour and takes a lot of time of his family members. Therefore the client is only allowed to phone his mother for half an hour a week and is prohibited to phone his brothers…. This decision stems from mother and as support staff we understand this.
>
> (Key worker, client 2)

The clinical file of this client reports, without mentioning a reason, that the client 'is allowed to phone his mother once a week for half an hour'

A second fragment describes a similar theme; according to the person with moderate ID the justification for the prohibition to possess a mobile phone stems from her mother, which is supported by support staff. The client mentions the following:

> Client: No, no, I am not supposed to have a telephone. No, no, that is not allowed. No, I do not have a phone or a mobile phone…
>
> Interviewer: Why is that?
>
> Client: The staff. Uh... and my mother does not like it at all...
>
> Interviewer: Can you tell me why you are not allowed to have a phone?
>
> Client: It is because… it is not allowed for me to have contact with boys for my own safety.
>
> Interviewer: How is it for you not to phone or text boys?
>
> Client: I think that's okay. It is better not to phone them.
>
> (Client 3)

The key worker of the client states:

> Our client can make phone calls in the central living room with assistance of support staff. This is for her own good and for her safety. It is better that she does not have a mobile phone as stated by her mother.
>
> (Key worker client 3)

The clinical file of this client makes no further notification of this restriction.

In both examples, the justifications for the restrictions as provided by parents and which are considered beneficial for people with ID are supported by support staff, and are adopted by the people with ID themselves. Hence, people with ID seem to derive the justifications for restrictions from significant others like family members and consider these justifications as beneficial for themselves.

Disagreement by people with moderate ID

Besides agreement with applied restrictions which participants show, they also show protest against restrictions. Therefore, we identified disagreement as a third theme. In these latter cases, they verbally utter the wish to alter the restrictions, as mentioned both by participants themselves and their key workers. In response to the expressed wishes to alter the restrictions, support staff indicate the willingness to explain the reasons for the applied restrictions, though the altering of the restriction itself is not mentioned. Hence, the protest from people with ID is recognized, but does not lead to changes in care. Where support staff emphasize the importance of maintaining the health of the people with ID, clients stipulate the importance of respecting their privacy. This is the case in the following example where a client protests against support staff putting her medicine in the bathroom when she is taking a shower:

> I do not like it when support staff bring me medicine while I am taking a shower. That is not okay, but they are still doing it. I do not like that. They can put the medicine on the table in my room when I am ready taking a shower. I do not forget to take my medicine. (Client 1)

The key worker of this client provides the following reason for this restriction:

> We know that our client does not like it that we enter her bathroom. But for our client it is necessary to take her medicine. If the medicine is placed in her bathroom, she can take them directly after taking a shower. It makes it more clear for the client that the medicine should be taken. (Key worker, client 1)

The clinical file of the client does not provide any description of or restrictions in the way the client has to take her medicine.

In this case, support staff seem to act according to classic medical values as 'causing no harm' and beneficence. The participating person with ID however dissents from support staff on the basis of other values, i.e. her dignity and privacy. She does not want to be seen undressed and is confident that she can remember to take her medicine ('I do not forget to take my medicine'). Support staff on their side focus on the health and safety of the person with ID. They want to exclude the possibility that the person with ID forgets to take her medicine. This emphasis on the health of the person with ID is understandable due to staff's responsibility to prevent clients from harm, but the perspective of the client, including the wish for privacy and dignity, is in this case ignored.

Another case in which a participant shows protest is illustrated in the next example. The client in this example wishes to have more privacy in the late evening to spend more time on the iPad:

> Client: I think the staff are a little bit too strict. They control me when I am using my iPad. I like to use my iPad also after ten o'clock in the evening till I am going to sleep…
>
> Interviewer: At what time are you going to sleep?
>
> Client: Normally at half past ten…
>
> Interviewer: Why is it that you have to stop using the iPad?
>
> Client: My keyworker says that the iPad is emitting radiation, which is bad for me... just before sleeping. (Client 6)

The keyworker of this client justifies this restriction as follows:

> It is clear that our client wants to spend more time on the iPad in the evening… But research has shown that radiation from an iPad or mobile telephone is harmful for people just before sleeping. It influences the sleeping process. We explained this to our client and therefore we stimulate him to turn off the iPad before sleeping. (Keyworker, client 6)

In this example clients' wish to have more privacy to spend more time using his iPad is ignored by his keyworker using a questionable justification based on promoting the health of the client.

Discussion and conclusion

This study examined how people with moderate ID perceive and evaluate restrictions applied to them in daily care and to what extent people with ID agree with these restrictions. To that end, we conducted qualitative interviews with people with moderate ID regarding possible restrictions in five domains in daily life. Analyses showed that participants tend to agree with the applied restrictions. Moreover, they explained restrictions are applied for their own well-being, varying from promoting their physical and mental health to stimulating structure, safety and rest in their lives. Hence, participants describe that restrictions might be a justified means to live a structured life and might contribute to the promotion

of their well-being. In this sense, participants show communality with support staff who mention similar justifications for the application of restrictions (Hendriks, Frederiks, & Verkerk, 2008; Kultgen, 2014; Van der Meulen, Hermsen, & Embregts, 2016). However, these findings require some nuances. In their justification, participants mention the same reasons for the application of restrictions as their family members, they might even derive and internalize their justifications from them. On the other hand, support staff adopt the justifications of family members and apply restrictions for the participants which are initiated by family members, like the restriction to phone only once a week with a father or mother. Support staff of this participant are considering wishes of the family over client's autonomy. At least staff seem to take it for granted that they have to comply with the family's request for limited phone calls. They are transparent about restrictions for their client, but they are not departing from client's wishes and are not considering alternatives to permanent restrictions.

Analysis also showed a value based dissensus between support staff and the participants. Support staff seem to be attached to moral values as promoting health and safety of participants, which can conflict with other moral values like the protection of the privacy and dignity, which are important for the participants. In this sense, traditional care values like causing no harm and beneficence seem to oppose other more person centered values like respecting a person's privacy and dignity. Hence, support staff primarily focus on the health of the client, which is understandable because they have to provide good care, but they seem to lack awareness of the client's perspective insofar other values than the health and safety of the client are at stake. Therefore, taking into account the perspective of people with ID asks for reflection and a broader moral sensitivity by support staff (Klaver, & Baart, 2011; Tonkens, & Weijers, 1999). This moral awareness requires effort, exercise, patience and also sensitivity to more person centered values (Van der Zande, Baart, & Vosman, 2013). To ensure that restrictions are applied for their well-being, which encompasses more than the physical health of the clients, it is essential that support staff are attentive to the needs and wishes of their clients (Arrey, & Copeland, 2014) and act as advocates for their clients and considering alternatives to permanent restrictions. By building up a trusting and professional care relationship (Embregts, 2011; Van Heijst, 2009; 2011) with

space for the client's own perspective, staff are more able to attune to the wishes and needs of people with ID. More attention of support staff to values like privacy and dignity of people with ID can be helpful in this respect.

However, attitude of support staff is difficult to influence compared to knowledge and skills, which can be trained in a more straightforward way (Van Oorsouw, Embregts, & Bosman, 2013). Nevertheless, there are also studies which illustrate that attitude can be trained (Van Oorsouw, Embregts, Bosman, & Jahoda, 2014; Zijlmans, Embregts, Gerits, Bosman, & Derksen, 2011). Hermsen and Embregts (2015) plead for reflective practice in social work education and coaching, and formulated guidelines to promote unconditional care in relationships with care receivers (see also Van Heijst, 2009; 2011). Based on a care ethical approach, unconditional care focuses on seeing the client as a person, implying that every person needs attention, trust and a feeling of freedom of choice. In this respect the five accomplishments (O'Brien, 1992; Murray & Lakhani, 1998) which constitute a value-based framework to provide support to people with ID can be helpful. For professionals to take into account three of these five aspects, i.e. choice, respect and relationships can result in a more constructive instead of restrictive approach. Engaging into a respectful dialogue with people with ID, will enable support staff to decide in partnership to what extent wishes are realizable.

Although this study give us insight in the perception and evaluation of the participants with moderate ID, the transferability of the findings is possibly limited as the study is conducted within only one care organization. The way daily care is provided as well as the culture might differ between organizations. Therefore, more research is needed among people with moderate ID receiving daily care in different care settings to achieve saturation on a theoretical basis. A second limitation concerns the response categories that were used to evaluate daily care, participants were able to choose between three response categories, i.e., 'good' (thumbs up), 'could be better (thumbs sideways)', and 'not good' (thumbs down). The response category 'could be better' was piloted and was found to be an understandable category for participants, but it does not represent a mid-point in terms of

language. As a consequence the results should be interpreted with caution. A third limitation concerns the IQ test we conducted. The score derived from the IQ test indicated that participants have an IQ <55, thereby enabling us to verify that participants did not have a mild intellectual disability (IQ <55). The test could not discern between moderate and severe ID however. To include people with moderate ID and exclude people with severe ID, we used information from participants' clinical files in which they were described as clients with moderate ID as well as information provided by two health psychologists of the care organization who diagnosed the clients as people with moderate ID.

A strength of this study is the development of a method for collecting qualitative data amongst people with moderate ID themselves. Research in which people with moderate ID are interviewed is scarce. Most research is conducted by means of proxies (e.g., support staff or family members) rather than gathering information from people with moderate ID themselves. Our research method provided the possibility for people with moderate ID, who have limited verbal capabilities, to speak for themselves as stated in the UN Chronicle 'Nothing about us, without us' (2004). Furthermore, the triangulation of sources obtained an overall and holistic picture of the research objective. In describing the research method in detail, we did try to make an impetus for further research among people with moderate ID.

To conclude, via an extensive, tailored research method, especially designed for people with moderate ID, we investigated the perception and evaluation of restrictions in daily care by people with moderate ID. Results showed that people with moderate ID who participated in our study tend to agree with the restrictions in daily care. They, as well as support staff showed communality in their perception and evaluation of restrictions. However, participants with ID also showed dissent from support staff regarding the application of restrictions, especially when their privacy and dignity was at stake. Therefore, it is advisable that support staff also develop moral sensitivity for these personal values. Finally, people with moderate ID tend to take over the justifications of family members. Further

research amongst family members of people with ID is required to provide more insight in their evaluation of restrictions and their influence on support staff who apply these restrictions.

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Chapter 4

Perspective of relatives on restrictions applied to their family members with moderate intellectual disability

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Abstract

The application of restrictions plays a great part in daily support of people with moderate intellectual disability (ID). In this study we examine the evaluation of relatives of restrictions applied to their family members with moderate ID. Relatives are key and permanent figures in the lives of people with moderate intellectual disability. Moreover, relatives in their role as representatives are authorized to make decisions in case people with moderate ID are not able to oversee the consequences of their actions. To explore relatives' evaluation of restrictions, we conducted semi-structured interviews with 10 relatives. Qualitative analysis was carried out using a thematic approach. We found that respondents consider restrictions necessary when they promote physical well-being, safety and indistinctive, 'normal', appearance of their family members with ID. In applying these restrictions a 'rules are rules' and a 'tailor-made rules' approach can be discerned. The 'tailor-made approach' provides space for dialogue with people with moderate ID. In this dialogue the criteria of proportionality, effectiveness, and subsidiarity are helpful. In using these criteria, the application of a restriction has to be in proportion, has to lead to the desired effect, and, finally, should be as unintrusive as possible for the person concerned. As such, it is recommended that, in dialogue, support staff, people with moderate ID themselves, and their relatives seek ways to examine what kinds of restrictions are justified for people with moderate ID.

Introduction

In the care for people with moderate intellectual disability ID (IQ 35/40–50/55; APA, 1994), the current focus lies on supporting them to live their own lives and to make their own choices without restricting them. This focus is in line with the UN convention, which stipulates 'the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities' (UN, 2006, article 1). In line, the Dutch Care and Coercion Act (2018) also promotes freedom of choice for people with ID. The Act states that, in addition to severe restrictions, like isolation or being forced to take medication, less severe restrictions, such as restricting people with ID in using means of communication or the amount of food-intake, can also be considered as involuntary care (article 2.1h). In this study, the focus will be on these 'less severe' restrictions applied in the daily lives of people with moderate ID living in a residential setting. According to their support staff, daily life restrictions are applied in the domains of eating and drinking, hygiene, social contacts, means of communication, and bedtimes (Van der Meulen, Hermsen, & Embregts, 2018a). Examples of these restrictions are the constraint to take a daily shower (domain hygiene) or restrictions concerning staying up at night (domain of bedtimes). Support staff explain that these restrictions are applied to contribute to physical well-being, safety or structure for people with moderate ID. Hence, restrictions in daily care have to be applied in a careful and conscientious way. The perspective of people with moderate ID themselves is key in this respect. In a previous study the present authors found people with moderate ID living in a residential setting themselves to confirm the existence of daily life restrictions. Taking into account that their responses might be socially desirable, people with moderate ID generally show agreement with these restrictions, indicating that these restrictions contribute to their own physical well-being, safety and structure, and prevent others from inconvenience. However, when a disruption in their privacy or infringement of their dignity is at stake, they show disagreement (Van der Meulen, Taminiau, Hertogh, & Embregts, 2018b). In evaluating these daily life restrictions, people with moderate ID attach great value to the view of their relatives, which seems to be guide for their own opinion-making (Van der Meulen et al., 2018b).

Relatives indeed play an important role in the lives of people with moderate ID during their whole lifespan. Social networks of people with (moderate) ID are often small and restricted to their relatives and support staff, on whom they are strongly dependent for social and emotional support (Lippold, & Burns, 2009). Although there is a wide range of individual profiles within the group of people with moderate ID, they all have more or less severe problems with conceptual and rational thinking and adaptive behavior (APA, 2013). These limitations result in a compromised capacity to reflect on the implications of their actions and decisions with respect to their own and others' well-being. Therefore, relatives are often legally authorized to make decisions on behalf of their family member with moderate ID (Care and Coercion Act, 2018). As such, they have a key role with respect to the application of restrictions in the lives of people with moderate ID, as both the guide in decision-making for people with moderate ID and from a legal perspective. Since restrictions should only be applied in the interest of people with moderate ID (Dörenberg, Embregts, Van Nieuwenhuijzen, & Frederiks, 2013), relatives have great responsibility when it comes to the decision to apply restrictions to protect their family members from harm. Conflicts may arise between what is considered 'best-interest care' by relatives and the desires and preferred choices of people with moderate ID themselves. According to care ethics, in this possible tension between the self-determination of people with moderate ID and their protection from harm, the well-being of people with moderate ID should be the guide, and the solidarity of relatives to promote the well-being of people with ID is required (Tonkens, & Weijers, 1999; Verkerk, 2001a). Hence, in addition to the perspective of support staff and people with moderate ID themselves, it is of great importance to investigate how relatives evaluate daily life restrictions of family members with a moderate ID living in a residential setting. To the present authors' knowledge, studies conducted on this topic so far focus on more *severe* restrictions such as fixation and separation as applied to people with moderate ID *and challenging behavior* (see, e.g., Elford, Beail, & Clarke, 2010; Heyvaert, Saenen, Maes, & Onghena, 2014). In these studies, relatives describe the application of restrictions as an attempt to strike a balance between providing freedom and safety for their family members with ID (Elford et al, 2010). The present research question is more focused on

these 'less severe' and more subtle restrictions applied in daily life of people with moderate ID: How do relatives of people with moderate ID evaluate restrictions in daily care for their family members with moderate ID living in a residential setting? This study focuses on relatives who are often parent(s) or sibling(s) of the person with ID in their role as legal representatives, and with whom they often have close emotional ties (VGN, 2017).

Method

Respondents

Permission to interview relatives of people with moderate ID was granted by the Ethical Review Board of Tilburg University, the Netherlands (EC-2016.44). In addition, the care organization where the family members with moderate ID reside also granted permission for this study. Participating relatives received an information and consent letter, explaining the aim and background of the study. In the information and consent letter, researchers explained that all information given by the respondents would be made anonymous and treated confidentially. Next, the researcher explained in the information letter that the interviews would be audio-recorded and that respondents were free to end the interview at any moment without negative consequences. Furthermore, in the consent letter it was stated that the data would be stored safely for 15 years according to the guidelines of Tranzo, Tilburg University. The respondents were selected by purposive sampling (Palys, 2008). Potential participants were selected in consultation with the health psychologists working at the care organization at which the relatives with moderate ID reside. Because of their insight into the social network of their clients with moderate ID, the health psychologists were able to indicate potential participants meeting our (purposive) sampling criteria (see Analysis for more detailed information about the sampling procedure). In all, 15 relatives were asked to participate in this study. Five relatives, including relatively older and younger potential respondents, were not willing to participate and did not provide a clear explanation for their refusal (e.g., "I think it is better that you ask someone else for

your research"). According to the process of recruitment they did not have to mention any reasons for refusal.

Table 1 *Demographic characteristics of relatives of people with moderate ID*

Respondent	Age of respondent	Age of person with ID	Relation to person with ID	Profession
1	68	66	Brother	Manager
2	60	34	Mother	Teacher
3	63	53	Brother	Teacher
4	62	30	Father	Engineer
5	44	15	Mother	Care worker
6	51	49	Sister	Care worker
7	79	35	Mother	Housewife
8	63	39	Father	Construction worker
9	44	53	Sister	Secretary
10	56	62	Sister	Entrepreneur

Procedure

Semi-structured interviews were conducted in which the interviewer asked relatives to provide information on the restrictions applied to their family member with moderate ID during daily care and to subsequently share their perspective on these restrictions. Prior to the interview, the interviewer had checked the clinical file of the person with ID for restrictions in daily care for which the care organization and relatives had given permission. Checking the clinical file was done to be able to include restrictions in the interview when the respondents themselves did not mention these

particular restrictions. In these cases, the character of the interview altered from a nondirective to a directive semi-structured interview (the interview guide is provided in Appendix 1). In the interview, the interpretation of what was meant by daily life restrictions was left open to the respondents, although in the information letter a few examples were mentioned regarding bedtime restrictions for people with moderate ID and restrictions regarding social media, for the purpose of facilitating the dialogue between interviewer and respondent. Prior to data collection, pilot interviews were held with two relatives (other than the 10 participating relatives). Based on this pilot, a few vocabulary changes were made for the sake of clarity and uniformity. After this, the interview guide proved to be useful for an open dialogue about the evaluation of daily life restrictions.

Analysis

Qualitative analysis of all interviews was carried out during the phase of data collection to provide the researchers the opportunity to use increasing insights in each consecutive phase of data collection. The interviews were inductively coded by using a thematic approach (Braun, & Clarke, 2006), supported by Atlas-ti software (Muhr, 2005). The first four interviews were independently coded by two researchers. Intercoder agreement was determined by checking all codes of both researchers (Miles, Huberman, & Saldana, 2014), resulting in an agreement level of 95%. Next, all four researchers involved (APM, ET, CH, PE) discussed these findings. The following interviews were coded by one researcher (APM) and systematically checked for quality, e.g., for bias, by a second researcher (ET) in line with guidelines for qualitative research (Miles, Huberman, & Saldana, 2014, p. 312). Each interview was analyzed prior to recruiting the following participant and conducting the next interview. In this way, the researchers were able to sample consecutive respondents purposively based on data gathered from the previously conducted interviews. In discussing the first four interviews, the research team decided to include two younger respondents since the research population till then consisted of respondents only in the age range of 62–68 years. Belonging to another generation, younger relatives might have a different view on restrictions applied to their family members with moderate ID.

With six interviews conducted and analyzed, the research team discussed that younger relatives in the range of 44–56 years of age were indeed more critical of the application of restrictions to their family members with moderate ID. Since all six respondents had a higher education level or worked themselves in caring for people with ID, it was then decided to approach two respondents with professions for which no higher education is required and who had no occupation related to caring for people with ID. Eight interviews were then conducted, and after the analysis of these eight interviews by three researchers (APM, ET, PE), it was concluded that information from respondents with a lower education level or with no profession related to caring for people with ID did not yield new findings. Therefore, it was decided to include two more siblings younger than 60 years of age to obtain balance in the number of participating parents and siblings and to obtain better balance in the age of respondents (i.e., six respondents older than 60 and four respondents younger than 60). After the analysis of all 10 interviews with the research team, no new themes emerged; therefore, it was decided that data saturation was achieved.

Findings

In analyzing the data, three themes were identified. First, it was found that relatives mention several justifications for applying restrictions to their family members with moderate ID. Subsequently, it was found that relatives use two different styles to apply restrictions, i.e., the style “rules are rules” (restrictions just have to be followed) and the style “rules have to be tailor-made” (restrictions need to be individually adjusted to their family member with moderate ID).

Justifications

In their evaluation of daily life restrictions for their family members with moderate ID, all respondents stipulate that the application of restrictions may be necessary to promote the well-being of their family members. These restrictions are applied by support staff as well as by the respondents themselves. Respondents state that due to their intellectual disability, their family members with moderate ID may

lack the awareness and judgment of what is the best thing to do or what is in their best interest. In this respect, restrictions can be helpful to guide their family members with moderate ID in the "right direction". The following justifications for applying restrictions were discerned. Respondents endorse restrictions if they promote:

- the physical well-being of their family members with moderate ID.

In this respect, restrictions to maintain good health as well as restrictions to prevent family members with moderate ID from becoming obese are mentioned. Examples are restrictions related to the frequency of physical exercise (e.g., daily exercise of half an hour on the home-trainer) or dietary restrictions (e.g., the restriction not to eat unhealthy food or restrictions with respect to the amount of food intake). For example, a father of a 39-year-old daughter mentions the following dietary restriction:

> "To avoid that [names] becomes obese, she is allowed to eat two slices of bread in the morning and two for lunch. Support staff do check this accurately." (Respondent 8)

Respondents are concerned about the physical condition of their family members, since this is perceived as being vulnerable. In restricting their family members from eating too much and to oblige them to exercise, respondents try to prevent their family members with moderate ID developing physical complaints.

- the safety of family members with moderate ID.

Respondents mention restrictions aimed at protecting their family members with moderate ID from dangerous situations in which they could get injured (e.g., the restriction not to be allowed to ride a bike alone) or restrictions concerning social contacts with unfamiliar people with the (perceived) risk of abuse. A mother of a 35-year-old daughter with ID describes her fear about her daughter having contact with unknown individuals:

> "I just do not want that she visits places where we do not know the people. In case people make unwilling advances to her I always say, 'They have to keep their hands off you.'" (Respondent 7)

Analysis indicated that fear for what might happen to their family member was motivated by either concrete dismal experiences in the past or by the mere thoughts of possible risks.

- a 'normal' indistinctive appearance of their family members with moderate ID.

According to respondents, their family members with moderate ID have to wear clean clothes, and the combination of clothes has to be suitable and result in a 'normal', indistinctive, appearance to make their relative fit into the daily street scene. In the following example, a respondent describes his difficulties with the way his brother likes to clothe himself:

> "I do not want to give my brother too much freedom in choosing his own clothes. He had periods in which he wore three or four sweaters combined with some t-shirts at the same time. That was not normal. I think it was a way to attract attention." (Respondent 3)

Respondents indicate that they do not like it when family members with moderate ID receive attention because of unusual clothes. They are not so much worried about the teasing or humiliation of their relative with moderate ID, but they in particular stress the attention-seeking attitude of their relative, which is abnormal in their eyes.

Styles of applying restrictions

All respondents stipulate the importance of applying restrictions to their family members with moderate ID. In applying restrictions, two styles were identified:

- *"Rules are rules"*

Some of the respondents (nos. 1, 2, 3, 4, 7, and 8) indicate that restrictions just have to be followed in all cases, even when their family members with moderate ID might wish to alter these restrictions. In cases when their family members with moderate ID protest, these respondents seek ways to maintain the restrictions. To realize this, they contact the support staff in order to be involved in the process of caring for their family member with ID. Analysis showed four strategies in which respondents deal with

daily life restrictions or urge support staff to deal with daily life restrictions in cases where their family members with moderate ID protest:

- Explaining the background of the restriction and mentioning the negative consequences in case their family member with moderate ID does not follow the restrictions. For example: “If you eat too much, you will get obese and then you cannot walk anymore.” (Respondent 8)
- Offering two alternatives that are perceived as acceptable by the respondent. For example, “Do you want to buy this t-shirt or the other one?” (Respondent 2)
- Using an argument of a competent authority to persuade the person with moderate ID. For example: “The dentist has said that you have to put in your dental prosthesis.” (Respondent 3)
- Being firm in adhering to the restrictions without adapting them. For example:

  “My son has to wear his new shoes instead of the old, shabby ones. He may protest as long as he wants, but he will wear his new shoes.” (Respondent 4)

It is the opinion of these respondents that support staff, who apply the restrictions in the context of the service provider, should stick to the restrictions. In general, respondents have the feeling that staff are aligned with them and are firm in applying the restrictions without adapting them. However, the adage “rules are rules” is not always endorsed by support staff. For example, the brother of a 53-year-old client expresses his indignation about the permissive attitude of support staff:

> “I am not satisfied with the fact that support staff give in too easily. As an example, my brother is missing a front tooth. Therefore, he has received a dental prosthesis. From the beginning, the staff was not motivated to encourage my brother to put in his dental prosthesis. Staff say to me, ‘if he does not want to, he just does not have to put it in.’ Staff are so permissive.” (Respondent 3)

In these cases, respondents state that support staff are not strict enough in applying and maintaining the restrictions that they consider important.

Table 2 *Styles and strategies of applying restrictions according to relatives of people with moderate ID*

Styles	Strategies
"rules are rules": restrictions just have to be followed by their family members with moderate ID	Mentioning negative consequences
	Offering two alternatives which are both acceptable to the relative
	Using the argument of a competent authority
	Being firm in keeping to the restrictions
"rules have to be tailor-made": restrictions are to be adjusted to their family members with moderate ID	Dialogue between support staff, relatives and people with moderate ID

- *Tailor-made rules*

In contrast to the style "rules are rules," other respondents (nos. 5, 6, 9, and 10) mention that in some cases, restrictions must be adapted. According to these respondents, adaption of restrictions is desirable in cases where organizational or medical protocols lead to static, inflexible care. In residential settings, restrictions can be applied to all clients as a form of collective care (Dörenberg, Embregts, Van Nieuwenhuijzen, & Frederiks, 2013). Respondents stipulate that in these cases, they want to have a say in the rulemaking process and in the application of restrictions. Not the prescribed protocol, but the interest of their family member with ID should be the guide. These respondents want to be involved in the care of their family member with moderate ID. The desired dialogue between support staff, relatives, and family members with moderate ID should result in tailor-made rules for their family members with moderate ID. Instead of fixed restrictions or protocols, these respondents prefer

personalized restrictions, which requires a certain form of flexibility from support staff and the care organization.

The following example shows a lack of dialogue about restrictions between support staff and a mother of a 15-year-old son. This mother was confronted with a restriction regarding the sitting posture of her son, following a medical protocol, about which she was not informed.

> "The restriction is that my son has to sit in a special chair in a special way to prevent him from developing an incorrect sitting posture. But our son is 15 years old, very lively, and he already has to sit three times a day at the table for his meals. Moreover, he throws the cushions off his special chair. Then I ask myself: 'Why did they not consult us as parents about this restriction?'' (Respondent 5)

The next example expresses a respondent's indignation at the fact that his family member with ID was obliged to visit the cinema:

> "My brother does not like to go to the movies. He has been scared of staying in dark places since he was young. A while ago he had to join the whole group of clients and go to the cinema due to the organizational restriction that every client joins common activities. There they let him stay alone in the foyer during the whole movie. Afterwards I accidently heard the entire story. At such moments I think to myself, 'What is going on here?' … Why not consult with me? I want to be part of it." (Respondent 3)

These examples make clear that these respondents ask to be engaged in the dialogue about rulemaking. According to these respondents, there may be reasons to adapt the restrictions and make them more tailor-made based on the idea that the well-being of the client is promoted by personalized care.

Discussion

In this study, we qualitatively examined relatives' perspectives on the restrictions applied in the daily care of their family member with moderate ID. All respondents indicated that the application of

restrictions in the daily life of their family members with moderate ID are justified since they promote their physical well-being, safety, or a 'normal' indistinctive appearance. Mostly relatively younger respondents (ranging from 44–56 years) emphasize the importance of adjusting restrictions to make them tailor-made for their family members with moderate ID, while relatively older respondents (ranging from 60–78 years) focus on the mere maintenance of restrictions in applying a so-called "rules are rules" style. In applying a "rules are rules" style various strategies are included, differing from a soft urging to a strong urging and coercion (Verkerk, 2001b). In interpreting the findings we use Verkerk's framework. She defines soft urging as an urging that is visible in persuading and convincing people. A strong urging emphasizes the negative consequence of not following a restriction, e.g., "If you do not follow the restriction, then this will be the unpleasant consequence." Coercion does not leave any space for freedom for the person concerned as that person is forced to follow the restriction. In our study, respondents who hold the adage "rules are rules" use urging, mentioning negative consequences if family members do not obey the restrictions. Also, they use coercion on their family members by forcing them to keep to the restrictions, without adapting them. In these cases, there is no way out for their family members with ID, i.e., they have to follow the restriction.

In our (previously) conducted studies, professionals (Van der Meulen et al, 2018a), people with a moderate ID themselves (Van der Meulen et al., 2018b), and their relatives indicate that restrictions in daily care are applied, and they simply provide the same explanations, i.e., restrictions contribute to clients' physical well-being, their safety, and daily life structure. Relatives, however, provide in our study an additional rationale in indicating that restrictions should also be applied to promote an indistinctive appearance for their family member with moderate ID.

Knowing that there might be morally acceptable justifications to apply restrictions (Care and Coercion Act, 2018), people with moderate ID who are at serious risk of becoming a victim of sexual harassment may be persuaded not to contact unknown or unfamiliar individuals. Morally much more complicated is the use of coercion in cases where people with moderate ID are not willing to wear 'normal' and decent clothing or a cosmetic dental prothesis for reasons of appearance. If there is no indication that

wearing non-ordinary clothing leads to danger or harm for the person with ID (such as sexual abuse), the justification to restrict the person with ID by coercion seems questionable in terms of power dynamics. This is surely the case in the examples of family members with moderate ID who are obliged to wear neat shoes or a dental prosthesis. Care which is considered in the 'best interest' by relatives might be in conflict with clients' own perceptions. In these cases, relatives' wishes not to attract the public's attention, which they perceive as uncomfortable, might outbalance the sense of accomplishment that persons with moderate ID experience in putting together an outfit or choosing which shoes to wear. Since this freedom to make one's own choices and execute them accordingly enhances experienced self-determination (Verdugo, Navas, Gómez, & Schalock, 2012), an open dialogue with respect to best interest care is of great importance in decision-making with respect to applying or maintaining restrictions (Taylor, Cobigo, & Ouellette-Kuntz, 2019; UN, 2006, Article 12.3; Williams, & Porter 2015). Perhaps consultations about the individual support plan (Herps, Buntinx, Schalock, Breukelen, & Curfs, 2016) offers a good point from which to start a dialogue between support staff, people with moderate ID, and their relatives about restrictions.

Furthermore, for a justified application of restrictions, the criteria of proportionality, effectiveness, and subsidiarity can be helpful (Berghmans, 1992; Dörenberg, Embregts, Van Nieuwenhuijzen, & Frederiks, 2013). In using these criteria, the application of a restriction should be in proportion, should lead to the desired effect, and, finally, should be as unintrusive as possible for the person concerned. As such, it is recommended that via dialogue support staff, people with ID themselves, and their relatives seek ways to examine what kinds of restrictions are in proportion, effective, and as unintrusive as possible for people with ID. This recommendation especially counts for support staff who collaborate with relatives who are in favor of the "rules are rules" style. According to NICE guidelines, people with ID need to be invited to discuss their preferences in order to individualize their care. It must be ensured that care and support for people with intellectual disabilities is tailored to their needs, strengths, and preferences and is not determined solely by their level of intellectual disability (NICE, 2019). This means that in the case that restrictions are necessary for the well-being of

the family member with ID based on the promotion of safety and physical well-being, they have to be 'tailor-made'.

With respect to possible patronization in deciding for the persons concerned what is best interest care, we should also critically reflect on our own procedure in recruiting participants for this study. Health psychologists of the care organization helped us to recruit relatives, but in this process of recruitment we only informed their family members with moderate ID. We did not ask them for permission to interview their relatives or to check their clinical files. In interpreting the findings of this study, another limitation should be taken into account; the sample size (10 respondents) was small and based on one particular care organization. For this reason, the findings of this study, as is the case in most qualitative studies (Verschuren & Doorewaard 2010), cannot represent a greater number of relatives of people with moderate ID. This study did not focus on frequencies, however, but on the exemplary character of the issues discussed (Hertogh, The, Miesen, & Eefsting, 2004). Therefore, via purposive sampling, the researchers stepwise selected respondents who differed in age and education level in order to achieve a wide range of variation in respondents. Post-validation of our results with the respondents would have further strengthened trustworthiness of our findings, however.

The strength of this study is the focus on the relatives of people with moderate ID and without challenging behavior with regard to daily life restrictions, which, as far as the authors know, was lacking in the current literature. Because of their significant role in the lives of their family members with moderate ID, insight into relatives' perspectives of daily life is pivotal in stimulating clients' self-determination.

Conclusion

Relatives of people with moderate ID living in a residential setting indicate that applying restrictions in daily care for their relatives is necessary to promote their well-being. Because of the dependency of people with moderate ID on their relatives, these relatives should carefully balance (a perceived) avoidance of harm by applying restrictions on the one hand and stimulations of self-determination of

their family member on the other. It is recommended that best interest care for people with moderate ID, which could also entail the application of restrictions, is decided upon in a conversation between people with moderate ID themselves, their support staff, and their relatives.

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Appendix 1 Interview guide

Welcome	Word of welcome/aim of the interview
Daily Care	1. Can you tell me how you experience the daily care offered to your relative? 2. What do you in general think of the daily care offered to your relative?
Restrictions	1. Do you know whether restrictions in daily care are applied to your relative? *If restrictions are applied, for each restriction consider the following questions:* 2a. Which restriction is applied to your relative? 2b. Do you know the reason for the applied restriction? 2c. Is your relative consulted about this restriction? 2d. Does your relative show resistance to the restriction? 2e. Do you as a relative agree or disagree with the restriction? Can you explain this? 2f. If you disagree with the restriction, do you feel the freedom to criticize it? 2g. How does your relative experience the restriction in your view?
Relation to support staff	1. How do you experience your relation to the support staff of your relative? 2. How do you experience your relation to other staff members of the care organization? 3. Do you feel free to express criticism? Can you explain this?
In the case that restrictions have not been mentioned till now	
Restrictions as described in the clinical file	In the clinical file of your relative the following restriction are mentioned. For each restriction consider the following questions: 1. Do you recognize this restriction? 2a. Do you know the reason for the applied restriction? 2b. Is your relative consulted about this restriction? 2c. Does your relative show resistance to the restriction? 2d. Do you as a relative agree or disagree with the restriction? Can you explain this? 2e. If you disagree with the restriction, do you feel free to express your criticism? 2f. How does your relative experience the restriction according to you?
Remaining questions	Are there any other issues regarding the application of restrictions which you like to mention?

Completion	I would like to thank you for your contribution to this interview. If you wish, you can receive an elaboration of this interview.

Chapter 5

Does Moral Case Deliberation change current views on restrictions?

Staff perceptions on restrictions

This chapter has been submitted for publication as:

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Abstract

Introduction

To promote sensitivity towards the perspective of people with moderate ID in applying daily life restrictions, Moral Case Deliberation (MCD) might be an appropriate method. In this study, the extent to which MCD leads to changes in the perspectives of support staff is examined.

Method

Prior to and following a series of three MCD sessions on moral dilemmas commonly encountered in daily life care, interviews were held with 12 support staff across two teams. Participants were asked what they considered to be good care in the given dilemmas. Interviews were analysed inductively.

Results

Following the MCD sessions, the respondents tended to hold onto their perspective to restrict clients to provide them with structure, clarity and rest, as expressed prior to the MCD. However, some respondents adapted their perspective on restrictions and were willing to provide people with moderate ID more freedom after the MCD.

Conclusion

This study contributed to the evidence underlying MCD in mental health care and in providing insights into MCD with regard to daily life restrictions in the care of people with moderate ID.

Introduction

In the care of people with intellectual disabilities (ID), support staff apply restrictions to people with moderate ID in several domains of daily life, such as restrictions on bedtimes, on the amount of food intake and/or on the use of an iPad (Van der Meulen, Hermsen, & Embregts, 2018). In arriving at decisions concerning restrictions in the lives of people with ID, the perspectives of all stakeholders involved need to be taken into account (Heyvaert, Saenen, Maes, & Onghena, 2014b) in order to reach a balanced judgement on whether or not to apply restrictions. In various studies, the perspectives of support staff and relatives on the restrictions applied to their clients and family members with ID are examined (e.g., Elford, Beail, & Clarke, 2010; Griffith, & Hasting, 2014; Hertogh et al., 2015; Heyvaert, Saenen, Maes, & Onghena, 2014a, 2014b). More specifically, in previous studies support staff and relatives of people with a moderate ID endorsed daily life restrictions, indicating these restrictions contribute to the physical well-being, safety, structure and 'normal' appearance of their clients and family members (Van der Meulen et al., 2018; Van der Meulen, Taminiau, Hertogh, & Embregts, 2019). Moreover, relatives stressed the imperative role of support staff in the application and maintenance of these restrictions; in turn, support staff indicated that they indeed apply daily life restrictions in the interest of their clients, but that this causes moral distress to themselves at times (Van der Meulen et al., 2018). People with moderate ID (IQ 35/40 – 50/55) affirmed the presence of restrictions in their daily lives and tend to consent to them, indicating these restrictions contributed to their own wellbeing or that of others. The view of their relatives was of great influence in their own positive evaluation of restrictions, however (Van der Meulen, Taminiau, Hertogh, & Embregts, 2018). This is in line with the tendency of people with ID to acquiesce with important others like relatives or support staff (Heal, & Siegelman, 1995). Signs of protest were apparent when people with moderate ID felt their dignity or privacy were affected (Van der Meulen, Taminiau, Hertogh, & Embregts, 2018). In contributing to the self-determination of people with moderate ID, it is thus important to acknowledge the possible resistance of people with moderate ID and to promote support staff's sensitivity to the perspective of people with moderate ID themselves and any potential subtle signs of protest against restrictions

(Heyvaert, et al., 2014a, 2014b; Solvoll, Hall & Brinchmann, 2015). Moreover, care to which a person with ID shows protest or resistance, even when the signs are subtle, can be perceived as involuntary care according to Dutch law (Care and Coercion Act, 2018). In line with this law, applying daily life restrictions can be part of providing good care, but only insofar as these restrictions are in the best interests of people with ID and are decided upon in dialogue with them (Abma et al., 2006).

To promote the desired sensitivity and awareness of the perspective of the other, which is considered a relevant moral competency, the existing literature shows that moral case deliberation (MCD) might be an appropriate method (Spijkerboer, Van der Stel, Widdershoven, & Molewijk, 2016; Spijkerboer, Van der Stel, Widdershoven, & Molewijk, 2017). MCD can be defined as 'the methodological reflection on concrete moral cases among health care professionals' (Molewijk, Verkerk, Milius, & Widdershoven, 2008, p. 43). By examining what is morally right in a specific care situation, MCD contributes to the improvement of the ethical climate and the moral quality of the care process (Molewijk et al, 2008).

The contribution of MCD has been evaluated in mental health care organisations (Molewijk et al., 2008) with respect to moral dilemmas such as fixating or isolating clients. To the best of our knowledge, no evaluative research has been conducted on MCD a) in the daily care of people with ID, and b) with regard to daily life restrictions in the care of people with moderate ID. In this study, we have therefore examined the extent to which MCD leads to changes in the perspectives of support staff with regard to daily life restrictions applied to people with moderate ID.

Method

Participants & setting

Two teams of support staff from one care organisation supporting people with (moderate) ID in the eastern part of the Netherlands participated in this research. These two teams were selected out of

ten teams supporting people with moderate ID on the basis of their willingness to cooperate. Team A, which supports eight clients with moderate ID, consists of six support staff who all participated in this research; team B, which supports 11 clients with moderate ID, consists of eight support staff. Six of them participated in the research, the remaining two staff members refused since they felt unable to combine collaboration in this study with their working schedule. All participating support staff interviews were held before and after the MCD sessions. The clients supported by these support staff are people who are all identified in their clinical files as people with moderate ID. No challenging behaviour or psychiatric disorders are reported in these clinical files.

Table 1 *Demographics of Participating Support Staff*

	Team A	**Team B**
Gender		
Female	6	5
Male	0	1
Age (mean)	40 years (range 25-58 years)	47 years (range 24-58 years)
Work experience in the care of people with ID (mean)	22 years (range 5-41 years)	29 years (range 7-40 years)
Education		
Secondary vocational education	4	4
Higher vocational education	2	2

Intervention

We organised three sessions of MCD per team within a six-week period. Each session had an average duration of one hour and was audio-taped. The MCD sessions took place at the care organisation with

the first author (APM) acting as the facilitator. APM received formal training in MCD and has over seven years' experience in conducting MCD. In each MCD session, one vignette was discussed (session 1, dilemma 1 etc.), originating from our previously conducted research regarding restrictions applied to people with moderate ID (Van der Meulen et al., 2018; Van der Meulen, Taminiau, Hertogh, & Embregts, 2018). In the first vignette, the client has to *stop* an activity, i.e., switching off his iPad after 10.00 P.M.. The client is disappointed about this restriction being applied by support staff and wants to decide for himself at what time he stops using his iPad. In the second vignette, a client is *physically forced* to go to the day-centre. She does not want to go and tells support staff that she wants to stay at home. Support staff believe that the client has to go to her work and force her to go by pulling her arms. In the third vignette, the client wants to *start* an activity (making a phone call to his mother) but is prohibited from doing so. The mother of the client has difficulties with these telephone calls, since there seems no end to the stories of her son. Therefore, the mother has decided that her son is permitted to only phone her for half an hour a week.

To explore a wide range of ethical dilemmas and variations in the character and perceived intensity of the dilemmas, the first dilemma described is chosen due to its educational character, the second due to its organisational character and the third because of its relational character. Moreover, in a pilot study, support staff (other than the participants this manuscript reports of) considered these themes to be exemplary dilemmas in the care of people with moderate ID. For an extensive description of the vignettes, see the brief report related to this study (Van der Meulen, Taminiau, Nijs, Hertogh, & Embregts, submitted).

The MCD sessions in our study were organised in line with the dilemma-method, a structured and frequently used form of moral deliberation in health care organisations (Stolper, Molewijk, & Widdershoven, 2016; Van Dartel & Molewijk, 2015). According to this method, the facilitator asks the participants to describe two opposite sides within the discussed dilemma and to summarise the corresponding values belonging to both sides. Subsequently, values are to be weighed against each

other and participants discuss which values should prevail. This discussion ideally leads to a well-founded judgment in dealing with the dilemma. The role of the facilitator during the MCD is to structure and support the dialogue and stimulate the reflection process of the group. More information about MCD and the dilemma-method in general (Stolper et al., 2016), and specifically the results of a qualitative analysis of the current MCDs, can be found in the brief report related to this study (Van der Meulen, Taminiau, Nijs,, Hertogh, & Embregts, submitted).

Interviews

Permission to conduct this study was granted by the care organisation in which the study took place, as well as by the Ethical Review Board of XX University (EC-2018.78). In an information and consent-letter, it was stated that all information provided by the support staff would be treated confidentially and that their input would not influence the evaluation of their work. The consent letter also stated that the data would be stored for 15 years, according to the guidelines of XX University. During the interviews, support staff were given the opportunity to end their contribution to the study at any moment without providing a reason. All support staff of the two teams who participated in the research gave their written permission.

All participating support staff were interviewed individually in advance of the MCD sessions, as well as after the completion of the three MCD sessions. The interviews were semi-structured and lasted approximately half an hour. To systematically compare all of the answers given in the interviews prior to and following the MCDs, the same interview-guide was used in both instances. The interviewer (APM) described the aforementioned three vignettes at the start of the interview and consequently probed the interviewee by asking what he/she described as good care in the vignettes and to what extent the interviewee would meet the wishes of the client. In response to the answers of the interviewee, the interviewer asked for clarifications and explorations to deepen the content of the information provided.

Analysis

We first transcribed the 24 interviews, i.e.,12 interviews in advance of the MCD and 12 interviews afterwards. Subsequently, the transcripts were inductively coded using Atlas-ti software (Muhr, 2005). Using an inductive approach, codes were compiled on the basis of the data itself. From the 24 interviews, six transcripts (25%) were also systematically coded by a second researcher (ET) in line with the standards for qualitative research (Kratochwill et al., 2010). In cases of differences in coding, a consensus was negotiated. Since the same interview-guide was used in the first and second interviews, we could compare the answers provided prior to and following the MCD sessions. We searched both for similarities and differences in the content of the codes with respect to the application of restrictions and underlying perspectives. An analysis of the content of the codes per respondent was performed by two researchers (APM, ET) and discussed in the project-team (APM, ET, CH, PE).

Results

In exploring the extent to which MCD leads to changes in perspectives among support staff with regard to the application of restrictions to people with moderate ID, we identified that respondents tend to evaluate the vignettes in the same way prior to and following MCD (see Table 2). Respondents maintained the perspective that sticking to the restrictions is considered to be in the best interests of a client and their care. However, some respondents changed their perspective from a focus on sticking to the restrictions to a focus on adapting the restrictions to provide more freedom for the client (see Table 2). Since the vignettes differ in their character and perceived intensity (vignette 1 educational, vignette 2 organisational, vignette 3 relational), our findings will be described per vignette. With regard to the content of the MCD itself we refer to the brief report related to this study (Van der Meulen, Taminiau, Nijs, Hertogh, & Embregts, submitted).

Table 2 *Evaluation of vignettes by support staff prior to and following the moral case deliberation*

		Vignette 1-Pad	**Vignette Day-centre**	**Vignette Phone-rule**
Prior to the MCD	Sticking to the restriction	Respondents: 1,2,3,4,5,6, 7,8,9,10,11,12	Respondents: 1,2,3,4,5,7, 8,9,10, 11,12	Respondents: 1,2,3,4,5,7,8,9,10,11,12
	Adapting the restriction	Respondents: ---	Respondent: 6	Respondent: 6
Following the MCD	Sticking to the restriction	Respondents: 1,2,3,7,8,9,10	Respondents: 1,2,3,7,10,11	Respondents: 2,3,7,8,9,10,11,12
	Adapting the restriction	Respondents: 4,5,6	Respondents: 4,5,6,8,9,12	Respondents: 1,4,5,6

iPad Vignette

In the vignette with the iPad, the client with moderate ID has to stop using his iPad at 10.00 P.M.. Prior to the MCD, all respondents indicate that sticking to this restriction is providing good care because a client needs guidance from support staff to receive enough rest. Following the MCD, respondents tended to hold onto this view, stating that there are justified reasons to restrict a client in the use of the iPad just before bedtime, i.e. maintaining a clear day-and-night structure for the client in order to protect their physical and mental well-being. In cases in which the client receives enough time to spend with the iPad in the day, these respondents have no difficulties in restricting the client during the night.

In this sense, restricting is seen as a form of providing good care. The following example provides an illustration of this view:

> "During the day a client has to feel healthy. Therefore it is good care to provide a client a good night's sleep. After using an iPad late at night your sleep will worsen. I would say, let this client use his iPad another moment during the day and not late at night."
> (respondent 1 -second interview)

Some other respondents who first focused on sticking to the restriction were willing to adapt the restriction and provide the client with more freedom following the MCD. They stressed the importance of trust in a client with respect to developing his self-learning capacity. In their view, a client is allowed to make mistakes, i.e. 'dignity of risk' (Nay, 2002). They indicated that in case the client is really fatigued the next day after using his iPad late at night, client guidance is needed by imposing restrictions in his use of the iPad, but not beforehand. The space provided to clients to experiment is seen as good care.

For example, a respondent who wanted to restrict the client prior to the MCD is willing to adapt the restriction and to meet the wish of the client under certain terms following the MCD:

Prior to the MCD:

> "Good care is to draw a line as a team. Ten o'clock is the rule. As a support worker you have to stick to this rule and communicate the rule with the client. The client just needs his sleep."
> (respondent 5)

Following the MCD:

> "I am willing to give the client space to use his iPad after 10.00 P.M.. The MCD taught me that it can be a learning moment for him. Who knows, he may switch off the iPad in time. But, in case he really is tired every subsequent morning, we have to take some measures."
> (respondent 5)

Day Care Centre Vignette

In the second vignette, a client with moderate ID is forced by her support staff to go to the day care centre on Monday morning, although the client shows resistance. Prior to the MCD, respondents stipulate the necessity to stick to the restriction and maintain the day-structure of the client. Additionally, they stress practical organisational issues such as limitations in their working-time as justifications for maintaining the restriction. Following the MCD, respondents are inclined to hold on to this view. The same justifications as prior to the MCD were mentioned, as well as the fear of recurrence of conduct of the client. In case support staff give in to the wish of the client according to this view, the client will possibly misuse her freedom to stay home more often. The consequence for support staff is that they have to work longer to which they are not inclined, since normally their shift is over when clients go to their work. In the following example, we provide an illustration of this practical-organisational justification for sticking to the restriction:

> "The problem is that in case the client stays at home instead of going to her work, no support worker will be present at home anymore. As support staff, we leave after our shift and just close the door. So, even though it is against her will, the client has to go to the day centre… If we do not act like this, the next time we will have the same problem."
>
> (respondent 7 – second interview).

However, some respondents changed their opinion due to the dialogue within the MCD. These respondents told us that they now realise that physically forcing a client to go to her work has a great impact on them. We will clarify this in the following example.

Prior to the MCD, the respondent provides the same justification as mentioned above:

> "I cannot see it is a restriction. The client has to go to work, although it is unpleasant for her. As a support worker, I have to finish my work in the morning and cannot support this client anymore. It is time for me to go home." (respondent 12)

Following the MCD, this same respondent mentions:

> "After discussion during the moral case deliberation, I think I am more aware of the resistance this client shows… Two support staff grab her by the arm, that is really heavy. That is something different than just using words to guide the client in the desired direction… Yes, in the case of grabbing the client by the arm, you can speak of a serious restriction." (respondent 12)

Thus, for some respondents it has become clearer due to the MCD that coercing a client to go to work is not desirable. The MCD has clarified for them that physically forcing a client to go to the day care centre is more threatening than verbally persuading a client to go to work. These respondents mention that for one time an exception in a client's obligation to go to the day-centre should be made. They are willing to give the client a day-off. Furthermore, these respondents propose contacting the family of the client and inquiring whether 'things went wrong over the weekend', indicating this information might be helpful in case the client refuses to go to work again.

Phone-rule Vignette

The third vignette describes a restriction in phoning initiated by the mother of the client. The client in this vignette is only allowed to phone her for half-an-hour a week. After initial protests, the client resigns to this restriction. Prior to as well as following the MCD, respondents tended to stick to the restriction in phone calls in order to sustain the relation between the mother and the client. They indicated they would not be inclined to challenge the relationship between the mother and the client as there is a risk that the relationship between mother, client and support staff deteriorates. They stress that contact between the mother and her child needs the willingness of both sides.

Furthermore, support staff consider the mother to be responsible for the restriction in phoning. They indicate that they as support staff are not restricting, but the mother herself is. The following example provides an example of this view:

> "It is the mother, not the support staff, who has made the decision. The mother sets the boundaries. We have to respect that. It is not a form of good care to do something which the mother does not want. As support staff, it is better not to intervene between the mother and the client." (respondent 3 – second interview)

Next to this dominant view prior to and following the MCD, some respondents altered their view due to the MCD. Instead of maintaining the situation of weekly half-an-hour contact, their intention is to sustain the client in his wish to phone his family more often following the MCD. Support staff now state that it is their task to promote the interest of the client. It is seen as a form of good care that support staff contact the mother of the client or other family members to look for alternatives in order to promote more contact between the client and their family. This change in perspective is visible in the words of the following respondent. Prior to the MCD, the respondent mentions:

> "It is a pity that the family of the client acts in this way. But the mother has made this decision. In case the client would want to make more phone-calls with the mother, the contact between them would worsen. I think it is best to follow the will of the mother" (respondent 4)

Following the MCD, the same respondent states:

> "Deep inside the client wants to have more contact with his mother, that is what I have learned from our group-meeting ('Moral Case Deliberation'-APM). This is what he really wants. I would try to arrange something with the mother of the client. Possibly, the client can phone more

> often than he does right now. Maybe three times ten minutes a week instead of half-an-hour a week." (respondent 4)

In summary, we have found that respondents following the MCD tend to hold on to their expressed view prior to the MCD. The ethical deliberations about the vignettes sustained their opinion that it is necessary to keep to the restrictions and provide the client with physical and mental rest (vignette 1), day structure (vignette 2) and an enduring relationship with family (vignette 3). On the other hand, some respondents were inclined to adapt the restrictions and to provide the client with more freedom after the MCD. Due to the dialogue in the MCD, these respondents mentioned that they are more aware of the impact of a restriction for the client and are willing to take their wishes and needs seriously. This, in their eyes, is seen as good care.

Discussion

Our research focused on the question of to what extent MCD leads to changes in the perspectives of support staff with regard to daily life restrictions applied upon people with moderate ID. Our findings are twofold. First, we found that respondents tend to hold onto their previous view with respect to sticking to the restrictions in all the three vignettes. Both prior to and following the MCD, the view to restrict clients to provide them with structure, clarity and rest stayed dominant. In all three vignettes, this justification is pivotal; this is particularly the case in vignette 3 in which support staff seek ways to not disturb the existing relationship between the client, staff member and the mother. The applied restrictions are seen as best interest care, according to these respondents. They consider it necessary to care for the client's physical and mental condition (vignette 1), a structured day-rhythm (vignette 2) or an enduring relationship between the client and their family (vignette 3). This result is in line with our earlier research with regard to restrictions in the daily lives of people with moderate ID (Van der Meulen et al., 2018; Van der Meulen, Taminiau, Hertogh, & Embregts, 2018). In these studies, support

staff as well as relatives of people with moderate ID emphasise the necessity of applying daily life restrictions to provide clarity, structure, rest and safety to people with moderate ID. Our second finding is that for some respondents MCD leads to a new perspective in which restrictions may be adapted and in which the client is provided more freedom to fulfil his or her own wishes. We observed respondents changing their perspective from sticking to the restrictions for his or her own well-being to a perspective in which there existed more room for the wishes of the clients. We would like to make some remarks to these outcomes. First, restricting a client does not automatically mean that support staff show a lack of sensitivity for the client. Holding onto the perspective of restricting might be a justified choice and as such a form of good care in cases in which it promotes the well-being of the client and is applied in dialogue with the client (Van der Meulen, Taminiau, Hertogh, & Embregts, 2018). For instance, the arguments mentioned by respondents in the vignette surrounding restricting the client in the use of the iPad seem reasonable in case a client gets exhausted as a result of the use of the iPad. It is a form of sensitivity to focus on the physical and mental health of the client in case the client's health deteriorates. In the second vignette in which the client is forced to go to her work, the application of the restriction seems less defendable. In cases in which a client is physically forced to go to her work, there have to be urgent reasons to justify this coercion. More sensitivity for and openness to the wish of the client is desirable here. In the third vignette concerning the client who is restricted in phoning his mother, respondents tend to sustain the position of the mother of the client. The reasoning of the support staff, namely that they do not want to disrupt the relation between the mother and her child, is understandable, but can also be used as an excuse to avoid a conflict with the mother of the client. It seems desirable that support staff also feel free to act as advocates of their client (Van der Meulen, Taminiau, Hertogh, & Embregts, 2018) without losing respect for the wishes expressed by the family of client. In this case, support staff may start a dialogue with the mother of the client to look for alternative solutions. Second, besides the dominant tendency that MCD did not lead to new perspectives for these respondents, there were cases in which the opposite was true. Following MCD, these respondents stipulate that they are more aware of the impact restrictions may

have on a client, especially in case physical force is applied as in vignette 2. In this respect, MCD can be seen as a method to promote the quality of the care process (Hem, Pedersen, Norvoll, & Molewijk, 2015) and as a key to promote more attentiveness towards the viewpoint of the other (Molewijk, Verkerk, Milius, & Widdershoven, 2008; Spijkerboer, Van der Stel, Widdershoven, & Molewijk, 2016; 2017; Jellema, Kremer, Mackor, & Molewijk, 2017). Consequently, it seems to be advisable for care organisations to invest in this moral dialogue, potentially through MCD on a regular basis, but also through a multidisciplinary discussion among support staff and other professionals about the necessity of restrictions (Schippers, Frederiks, Van Nieuwenhuijzen, & Schuengel, 2018) may lead to more sensitivity and awareness of support staff.

Finally, several limitations are to be mentioned. The first limitation concerns the validation of this study and refers to the dilemmas discussed. These dilemmas did not originate from the teams of respondents themselves but were derived from earlier studies (Van der Meulen et al., 2018; Van der Meulen, Taminiau, Hertogh, & Embregts, 2018). Although these dilemmas were tested in a try-out and were considered as well-known dilemmas by support staff in both teams, they were hypothetical and not compiled on experiences with their own clients. As a consequence, the study focused solely on the opinions and perspectives of support staff and not on changes in their actual conduct. A second limitation is that the interviewer of the support staff was the same person as the MCD-facilitator (APM). Due to this dual role, respondents possibly provided socially desirable answers in the interviews in which the significance of MCD is stipulated. However, to diminish this possible lack of fidelity, we recorded all interviews. Additionally, the interview-codes were checked by two researchers (APM, ET). Furthermore, the quality of the MCDs, which were all recorded and transcribed, was checked by analysing whether all phases within the MCD were systematically processed.

The strength of this study is that its outcomes did not stem from questionnaires in which respondents have to evaluate MCD by self-descriptions, as is common practice in evaluating MCD (De Snoo-Trimp, Widdershoven, Svantesson, De Vet & Molewijk, 2017; Spijkerboer, Van der Stel,

Widdershoven & Molewijk, 2016; 2017). Self-descriptions in questionnaires may lead to socially desirable answers. Although this risk is also present in our study, it is minimalised by our qualitative approach in which we have accurately analysed the interviews of all participating support staff prior to and following the MCDs. In this way, this study contributed to an evidence-based underlying MCD. Moreover, this study provides insight into how MCD functions with regard to the theme restrictions in a care-setting for people with ID, whereas the evaluation of MCD is mostly conducted in mental-health settings. Conducting and evaluating MCD in the care of ID may increase the sensitivity and awareness of support staff for the perspective of the client.

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Chapter 6

Opening the black box of Moral Case Deliberation:

A content-analysis of Moral Case Deliberation sessions

This chapter has been submitted for publication as:

Van der Meulen, A., Taminiau, E., Nijs, S., Hertogh, C., & Embregts, P. (2020). Opening the black box of Moral Case Deliberation.

Background

In this brief report, we provide insight into the content of MCD sessions in which support staff jointly reflect on moral dilemmas in applying restrictions on the daily life of their clients with moderate ID.

Method

Content analysis was conducted on six sessions of MCD, in which the dilemma method was used.

Results

Support staff define the opposite side of dealing with the given dilemmas and their underlying motives and decision-making in whether or not apply restrictions.

Conclusion

This brief report contributes to opening the black box of MCD as an instrument of moral counselling in the care of people with moderate ID.

Introduction

In the care of people with intellectual disabilities (ID), support staff often experience moral dilemmas with respect to the application of restrictions on the daily life of their clients and whether or not these restrictions are to be considered as good care. For instance, in applying restrictions in the use of social media, which gives pleasure to the client, but is perceived by support staff as possibly resulting in, for example, negative consequences for their clients' physical wellbeing or leading to risky social contact (Van der Meulen, Hermsen, & Embregts, 2018). These dilemmas may lead to moral doubt or distress amongst support staff, especially in cases where a client clearly shows protest or when a client's reaction to the restriction is susceptible to multiple interpretations (Bannerman, Sheldon, Sherman, & Harchik, 1990; Heyvaert, Saenen, Maes, & Onghena, 2014; Van der Meulen et al., 2018). Furthermore, support staff within the same team may evaluate a client's reaction to a restriction in different ways, which might result in team members ambiguously dealing with the application of a restriction.

Moral Case Deliberation (MCD) might be used as an instrument for a team of support staff to jointly reflect on these dilemmas and is considered a form of ethical support (Jellema, Kremer, Mackor, & Molewijk, 2017). However, regarding the actual content of MCD, little research has been conducted (Svantesson, Silén, & James, 2018). The few studies that have been performed have tended to focus on participants' perception and evaluation of MCD (see, for example, De Snoo-Trimp, Widdershoven, Svantesson, De Vet, & Molewijk, 2017; Seekles, Widdershoven, Robben, Van Dalfsen, & Molewijk, 2016; Spijkerboer, Van der Stel, Widdershoven, & Molewijk, 2016; 2017). The outcomes of these studies show that participants of MCD become aware of other perspectives than their own due to the MCD. However, these studies do not focus on the actual themes discussed within the moral deliberations, nor on the underlying motives and outcomes of decision-making. MCD may even be seen as a 'black box' for the non-participant. Therefore, there is a need to capture the content beyond moral reasoning within MCD (Svantesson, Silén, & James, 2018). As such, we have conducted MCDs amongst support staff to examine the extent to which MCD leads to changes in perspectives with

regard to daily life restrictions applied upon people with moderate ID (Van der Meulen, Taminiau, Hertogh, & Embregts, 2019, submitted), and in doing so we decided to additionally analyse the content of the MCDs to open this 'black box'.

Method

A detailed description of the method is provided in the article related to this brief report (Van der Meulen, Taminiau, Hertogh, & Embregts, submitted). Amongst the variety of methods to conduct MCD (Van Dartel, & Molewijk, 2015), we used the dilemma-method, which is a structured and frequently used form of moral deliberating in health care (Stolper, Molewijk, & Widdershoven, 2016). In this method, participants discuss an ethical dilemma and are supported by an MCD-facilitator. The task of the MCD-facilitator is to structure and clarify the dialogue, thereby supporting the participants in phrasing the moral dilemma. The facilitator invites the participants to discern what they perceive as two opposite sides of dealing with the given dilemma. Subsequently, the facilitator stimulates a joint dialogue in which the motives underlying both opposites are explored. Finally, participants are requested to provide a well-considered decision in how they would deal with the given dilemma. The three vignettes discussed in the MCDs were as follows:

> 1) A client with moderate ID likes to spend his time on his iPad. He is not controlled in the websites he likes to visit. He is allowed to do what he likes using his iPad: playing games, watching movies, etc. However, the client is restricted in his screen time. In the evening after 10.00 P.M., he has to switch off his iPad. The client is disappointed about this restriction applied by support staff and wants to decide for himself at what time he stops using his iPad.
>
> 2) A 30-year-old client with moderate ID has stayed at her parents' home for the weekend. She returns to the care organisation on Sunday evening. On Monday, she does not want to go to her work and tells support staff that she wants to stay at home. Support staff believe that the

client has to go to work and force her to go by pulling her arms. The client shows resistance. Upon arriving at work, the client is still in a bad mood.

3) A client with moderate ID likes to phone his mother. During his calls, the client likes to tell her about all kinds of things that have happened in his life. His mother has difficulties with these telephone calls, since there seems to be no end to the stories told by her son. Therefore, the mother has decided that her son is only permitted to phone her for half an hour a week. The reason for this decision, according to the mother, is that the client cannot stop talking when he is on the phone, which is exhausting for others.

Two teams of support staff (group A and group B) providing care and support to people with moderate ID participated in this study. All participating support staff in the two teams, each comprising six staff workers, gave their written permission to participate in the research. After completing the MCDs, all six (2x3) sessions of MCD were transcribed verbatim. Subsequently, three researchers conducted content-analysis (SN, APM, ET) with respect to 1) the two opposite sides in dealing with the given dilemmas, 2) the motives which justify the described care belonging to both opposites and 3) the decisions the teams would make with respect to the given dilemma.

Results

The two opposite sides of the dilemma

In all three vignettes, the participants defined sticking to the restriction as described in the vignette as the first side of the dilemma. In the first vignette (i.e. restricting the use of the iPad after 10.00 P.M), however, the teams differed in the way they would stick to this restriction. Participants in group A would remove the iPad after 10.00 P.M, whilst the participants in group B would urge the client to turn off the iPad himself. Participants defined the second, or opposite, side of the dilemma in all three

vignette as the provision of freedom, i.e., no control in the client's use of the iPad (vignette 1) or telephone (vignette 3) and permitting the client to stay at home instead of going to work (vignette 2).

Motives underlying both defined opposites

In their joint dialogue, participants mentioned the following motives underlying the first side of the given dilemmas for sticking to the rules, namely the client's physical wellbeing, relatedness to family, clarity and structure, broadening of the client's world, normalisation and professional responsibility (Table 1 shows the distribution of motives per dilemma). The participants in groups A and B both named *physical wellbeing* in general as a motive to stick to the rules and more specific physical health, sleep deprivation and addiction were cited. Next, the *relatedness to the family* motive was mentioned. This comprises respecting the wishes of the client's family, protecting the relationship between the mother and the client and preventing the mother from becoming frustrated. In the vignette of the phone rule, a staff worker states, for example:

"In case you stimulate the client to phone his mother, whilst the mother does not like this at all, the client has a problem. The client will probably get a negative response from his mother…." (staff worker, group B)

Furthermore, in the vignettes of the iPad and day care centre both groups named *clarity and structure* as underlying motives for restricting the client, for example in providing the client with clear boundaries. According to the participants, sticking to the rules in these vignettes may also *broaden the world of the client*. For example, they indicate that there is more than only an iPad or in the vignette of the day care centre they perceive there is a need to meet other people. Next, *normalisation* was described in both groups regarding the dilemma of the day care centre, because the participants indicated that going to work is part of a normal life and "you cannot just decide not to go". In all, participants in both groups prefer to stick to the rules in the dilemmas because they, as professionals,

know what is best for the client. They perceive it is their *professional responsibility*, as direct support staff, to provide good care.

With respect to the opposite side of the dilemmas, participants named the following motives to provide the client freedom, namely the respect and self-respect of the client, self-determination, empathy and the maintenance of a good relationship between client and support staff (see Table 1). Participants were willing to provide freedom to the client, because then you *respect the client* and *stimulate the self-respect* of the client. According to the participants, it also increases the *self-determination* of the client. Furthermore, group A named *empathy* with the client as a motive for providing freedom to the client regarding the dilemma of the day care centre and telephone contact with the client's mother. In the described vignettes, participants understand the client's feelings of disappointment and frustration in cases in which their wishes were not fulfilled. As mentioned by a staff worker of group A with respect to the vignette of the day care centre:

"Feeling empathy with the client is an important value. It is a hard thing that the client has to go to a place where she does not want to go. In a certain way, I feel sorry for her" (Staff worker, group A).

In relation to the vignette of the iPad, the maintenance of a good *relation between the client and direct support staff* was named as a motive to provide freedom to their client.

Table 1. *Motives for sticking to the rules or providing freedom to the client*

	iPad Day	Phone							
						Centre			
		A	B	A	B	A	B		
Motives for sticking to the rules									
Physical wellbeing		**x**		**x**				**x**	
Relatedness to family				**x**				**x**	**x**
Clarity and structure				**x**	**x**	**x**			
Broaden the world of the client				**x**	**x**				
Normalisation					**x**	**x**			
Professional responsibility		**x**		**x**		**x**			
Motives for providing freedom to the client									
Respect and self-respect of the client		**x**		**x**	**x**				**x**
Self-determination of the client		**x**		**x**	**x**	**x**		**x**	
Empathy					**x**			**x**	
Relation between the client and support staff				**x**					

Dealing with the given dilemma

In the vignette of the iPad, groups A and B decided to provide the client with more freedom to use his iPad after 10.00 P.M.. However, this freedom would not be unconditional. If participants noticed serious sleep deprivation or a deterioration of the client's physical condition, they would revert to the restriction to switch off the iPad after 10.00 P.M.. A staff worker from group A describes this as follows:

"I think we should give it a try, but not without some control from our side. We could just start with giving the client some freedom in using his iPad after 10.00 P.M.. In case it gets out of hand, for instance

when the client gets really tired or feels really bad, we can always return to the old rule". (Staff worker, group A).

In the vignette of the day care centre, both teams chose to persuade the client to go to the day care centre. However, they would not physically force the client. Instead, participants would contact the family of the client and support staff at the day centre to explore a possible motive underlying the client's refusal to go to the day centre. A staff worker from group A states:

"I think it is a good thing to let the client go to the day centre. But why is it not possible to stimulate the client verbally to go to the day centre instead of two men physically grabbing her by her arms?…Furthermore, in an extreme situation such as this I should certainly contact the parents of the client." (Staff worker, group A)

In the vignette of the phone-rule, participants in group A decided to support the wish of the client to have more contact with his mother. They would be willing to contact the mother or other family members to explore the possibilities of broadening telephone contact between the client and his mother. Group B decided to stick to the rule in order not to disturb the relationship between the client and their mother. According to group B, maintaining a good relationship between the mother and the client is in the client's best interests. This point of view is clarified by a staff worker:

"In case we as staff push the mother of the client to phone more often, the relationship between mother and client will probably worsen. There is also a chance that the mother keeps more distance from her son, more than she already does. Perhaps the initiatives of our staff end in a quarrel between mother and son. We as support staff have a responsibility to maintain a good relationship with the family of our clients." (Staff worker, group B)

Conclusion

In this brief report, we discovered the actual content of MCDs centred around moral dilemmas in restricting people with moderate ID. In this way, we opened the black box of MCD and provided insight into moral counselling within the conducted MCDs. Specifically, this report provided an illustration of how staff supported by a facilitator reflected on three moral issues commonly experienced when caring for people with moderate ID. It clarified that staff by means of dialogue were able to explore the underlying motives of two opposing sides of the given moral dilemmas. Moreover, staff were able to achieve nuanced decision-making in dealing with the given dilemma. These findings may hopefully contribute to moral deliberations about dilemmas in the care of people with moderate ID, in which MCD may be a useful method.

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Chapter 7

General Discussion

The overall aim of the current dissertation was to examine how restrictions in daily care for people with moderate ID were evaluated by support staff, by people with moderate ID and by their relatives. In addition, Moral Case Deliberation (MCD) was evaluated as an instrument to promote support staff's sensitivity toward perspectives in evaluating restrictions other than their own such as the perspective of the client. In our **first study**, semi-structured interviews with 15 support staff were conducted, in which we asked them in which daily life domains they apply restrictions to people with moderate ID, and how they perceived and evaluated these daily life restrictions (study 1). Next, in our **second study** eight people with moderate ID were asked whether they experience restrictions in the daily life domains retrieved from study 1 and if yes, how they evaluated these restrictions. To promote the reliability of our study, interviews were conducted being close in time and place in which restrictions in a particular domain of daily life might occur, i.e., posing question with respect to possible restrictions in hygiene in the morning, in receiving social visits in the early evening, and with respect to bedtime later in the evening. In addition, triangulation of sources in collecting data was applied. After conducting the interview with the person with moderate ID, the clinical file of that person was systematically analyzed with respect to information regarding applied restrictions and the client's perception of these restrictions, and their key-support staff were interviewed about how they feel the person with ID him/herself perceived and experienced these restrictions (study 2). Subsequently, in our **third study** relatives' evaluation of daily life restrictions in the care for their family member with moderate ID was explored, by conducting semi-structured interviews with 10 relatives, who were also the legal representatives of their family member with ID. Besides the studies that focused on the evaluation of daily life restrictions, a practical tool for support staff to discuss these restrictions was evaluated in **study 4 and 5**. Aim was to examine to what extent MCD contributed to support staff's awareness of the perspective of the client. In contributing to supported decision-making of people with moderate ID, it is important to acknowledge possible resistance of people with moderate ID and to promote support staff's sensitivity to the perspective of people with moderate ID themselves and any potential subtle signs of protest against restrictions (e.g. Heyvaert, et al., 2014a, 2014b). To

examine to what extent MCD promotes support staff's awareness toward the client-perspective, three MCD- sessions were conducted in two separate teams of support staff (six in total). Following the dilemma method, in the MCD sessions moral dilemmas as commonly encountered in daily life care with respect to restricting clients with moderate ID, were discussed with the support staff members. In our **fourth study**, we described results retrieved from the interviews prior to and following the MCD sessions, with 12 support staff of the two teams, in which they were asked what they considered to be good care in the given dilemmas (study 4). In our **fifth study**, insight into the actual content of these MCD sessions was provided (study 5). In the current chapter, the main findings will be presented and discussed, followed by reflections on the methodology used and implications for daily practice.

Main findings

First, in **study 1** is found that support staff indicated to apply restrictions in the daily life of their clients. Restrictions were identified in the next daily life domains: eating/drinking, hygiene, means of communications, daily structure, relations and bedtimes. Second, in evaluating restrictions, support staff stipulated that restrictions are justified since, according to them, clients need 1) clarity (e.g. in helping clients what they are supposed to do, e.g. in traffic situations), 2) to stay in good health, (e.g. not getting obese) 3) to be kept out of danger (e.g. not getting in touch with, according to support staff, doubtful contacts) and 4) structure and rest (e.g. fixed bedtimes). In addition to providing information about the daily life domains in which they apply restrictions, and their evaluation of these restrictions, support staff also described the *way* they apply these restrictions when they see no alternative for the application of restrictions. Support staff indicated to use the following methods: a) *communicate with the client:* support staff indicate they are willing to explain the restriction to the client, and tell him/her the restriction is in the client's best interest, b) *getting to know the client:* support staff adapt the restriction in a more tailor-made restriction based on knowledge of the client and having a bond with him, c) *nudge the client:* support staff 'seduce' clients to follow the restriction,

particularly in situations where there seems no alternative to the restriction, e.g., seducing a client to go to bed in the evening, d) k*eep a distance from the client:* support staff tell their clients what they are (not) allowed to do, but they do not push them to do it, they remain at a certain distance, give clients some space and wait until clients do what they are told to , e) c*onfront the client:* support staff confront their clients with the activity that has to be done. They repeat the restriction, until the client has or hasn't acted according to the restriction f) *hide restrictions: support staff* camouflage the daily life restriction, e.g. clients who want to eat more than is supposed to be good for them, they get a small portion twice or the meal is spread out on the plate in such a way that the amount of food seems to be more.

Finally, support staff also provided information about their feelings with respect to applying restrictions, indicating they have difficulties with applying restrictions or dealing with them respectively. Despite the fact that they say that applying restrictions to people with moderate ID promotes their physical well-being, safety, structure, rest and clarity, they also indicate to experience moral difficulties with the application of restrictions. These doubtful feelings can lead to moral ambivalence, i.e., some support staff experience difficulties in finding a balance between supporting their clients and restricting them.

After finishing study 1, some changes were made. First, in study 1 the term 'restraints' was used to describe the research-subject instead of the term 'restrictions'. In the following studies the term 'restrictions' was preferred, because the term 'restraints' is often related to physical restraints such as fixation and separation against which clients protest (Heyvaert et al., 2015). Since our research focused on 'mild restraints' in daily care without a specific focus on physical interventions, the term 'restrictions' seemed more suitable for the following studies (chapter 3 to 7). Second, in the following studies the term 'relations' to describe a domain of application of restrictions was replaced for 'social contacts'. Since restrictions on 'social contacts' incorporate a broader field of contacts than restrictions on 'relations', e.g. restrictions in visiting people or receiving visits, it seemed more suitable to use the

wider domain name 'social contacts'. Third, in study 1 'daily structure' is named as a domain of restriction (obligatory day structure) as well as a justification of restriction (structure to provide clients clarity and rest). This may cause confusion. To provide more clarity in vocabulary in the following studies and to specify the term, providing 'structure' was only used as justification for the application of restrictions,

In the following two studies, people with moderate ID and their key-workers were interviewed (study 2) and their relatives (study 3) with respect to their perception and evaluation of applied restrictions in the daily life domains as found in study 1, i.e., eating/drinking, hygiene, means of communications, social contacts and bedtimes. The main findings of **study 2** are the following. Participating people with moderate ID recognized restrictions applied on them in their daily life. According to them these restrictions are applied to a) promote their own physical and mental health, e.g. restrictions regarding drinking and eating, b) promote their safety, e.g. restrictions in using their mobile phone to keep from contacts perceived doubtful by others, c) obtain structure and rest, e.g. restrictions regarding fixed bedtimes. Furthermore, results demonstrate communality between the participating people with ID and their key workers in their perception and evaluation of restrictions, in people with ID tending to comply with the applied restrictions. People with moderate ID who agreed with restrictions even seem to derive the justifications underlying this agreement from significant others such as support staff and relatives. However, participants were also critical about restrictions insofar they violate their privacy or dignity. Where support staff emphasized the importance of maintaining the health of the people with ID, clients stipulated the importance of respecting their privacy, e.g. in the case where a client protests against support staff putting her medicine in the bathroom when she is taking a shower.

Main findings in **study 3** demonstrate that all respondents consider the application of restrictions necessary to promote the well-being of their family members with ID. Respondents state that due to their intellectual disability, their family members may lack the awareness and judgment of what is the best thing to do or what is in their best interest. In this respect, restrictions can be helpful to guide

their family members with moderate ID in what they consider best interest care. The following justifications for applying restrictions were discerned. Relatives tend to agree with restrictions if they promote 1) the physical well-being, 2) the safety and 3) a 'normal' indistinctive appearance of their family members with a moderate ID. According to respondents, their family member with moderate ID have to wear clean clothes, and the combination of clothes has to be suitable and result in a 'normal', indistinctive, appearance to make the family member with ID fit into the daily street scene. Next, although all respondents stipulated the importance of applying restrictions to their family members with moderate ID, we identified two styles in which restrictions were applied. Some of the respondents indicated that restrictions just have to be followed in all cases, even when their family members with moderate ID might wish to alter these restrictions. This is the "*rules are rules"-style*. In cases when their family members protest, these respondents seek ways to maintain the restrictions in the following ways: 1) explaining the background of the restriction and mentioning the negative consequences in case their family member does not follow the restrictions, 2) offering two alternatives that are perceived as acceptable by the respondent, 3) using an argument of a competent authority to persuade their family member, 4) being firm in adhering to the restrictions without adapting them. Other respondents were in favor of the so-called *'tailor-made rules'* style. They focused on the dialogue between support staff, their family members with ID and themselves. These respondents mention that in some cases, restrictions must be adapted to better suit their family member with an ID. According to these respondents, adaption of restrictions is desirable in cases where organizational or medical protocols lead to static, inflexible care. Respondents stipulate that in these cases, they want to have a say in the application of restrictions.

In **study 4** and **5** we have evaluated a practical tool for teams of support staff to promote their sensitivity for the perspective of people with moderate ID in applying restrictions, being Moral Case Deliberation. MCD can be defined as 'the methodological reflection on concrete moral cases among health care professionals' (Molewijk, Verkerk, Milius, & Widdershoven, 2008, p. 43). We conducted MCD's with two teams of support staff based on three different vignettes describing restrictions

commonly applied in the daily life of people with moderate ID. The vignettes were based on three restrictions retrieved from our previously conducted studies (study 1, 2 and 3) against which the clients protested, i.e., vignette restriction in using the I-Pad, vignette forced attendance at day centre and vignette restriction in calling mother. All participating support staff were interviewed individually in advance of the MCD sessions, as well as after the completion of the three MCD sessions. Respondents were asked what they described as good care in each vignette and to what extent he/she would meet the wishes of the client in the vignette (study 4). To contribute to the knowledge base with respect to the actual content of MCD's, we additionally conducted content analysis of the transcripts of all six MCD's (study 5).

We found the following. First, in study 4 we identified that respondents prior and following the MCD's tend to consider the application of restrictions, as described in the vignettes, in the best interest of the clients. As a consequence, respondents tend to give little space to the fulfilling of clients' wishes, prior as well as following the MCD's. However, some respondents changed their perspective from a focus on applying restrictions, prior to the MCD's, to a focus on adapting the restrictions to provide clients more freedom in fulfilling their wishes, following the MCD's. Second, in analyzing the content of the MCD's in study 5 we found that teams, in line with outcomes out of the earlier three studies, prior to MCD as well as following MCD, were inclined to apply restrictions in order to protect people with moderate ID from harm. However, due to the dialogue in the MCD's support staff became more aware of the personal impact of restrictions for clients and were willing to take clients' wishes and needs more seriously. Summarized, on the one hand MCD confirmed support staff in already existing justification with respect to applying restrictions, on the other hand MCD may also be considered a tool by which support staff explore more insight in the perspective of others like people with moderate ID themselves. Therefore, we may conclude that MCD partly promotes support staff's sensitivity for the perspective of the other.

Reflection on the findings

The studies show coherence in findings (see Table 1). Support staff, relatives and people with moderate ID themselves tend to agree with restrictions in case they promote (respectively) the well-being of their client or relative with moderate ID or their own wellbeing. In justifying restrictions, all respondents mention the importance of promoting 1) good physical health and 2) safety. Next, both support staff and clients mention structure and rest as a justification. In addition to these justifications relatives of people with moderate ID state that restrictions also are allowed when they contribute to the 'normal', indistinctive appearance of their family member with moderate ID.

Table 1 *Justifications of restrictions according to support staff, clients and relatives*

Support staff	**Clients**	**Relatives**
Clarity		
Structure and rest	Structure and rest	
Good health	Good physical and mental health	Good physical health
Kept out of danger	Safety	Safety
		Normal appearance

In reflecting on these findings we would first like to address that restricting a client does not automatically mean that support staff or relatives show a lack of sensitivity for the client. Holding on to the perspective of restricting might be a justified choice and as such a form of good care in case it promotes the well-being of the client and is applied in dialogue with the client. The application of a restriction may even promote the freedom of a person. Here 'freedom' is understood as 'freedom to' (positive freedom) instead of 'freedom from' (negative freedom) (Berlin, 1969). Positive freedom is related to providing space for the growth and development of people. In this sense freedom is not

seen as freedom from undesirable involvement, but as freedom to fulfil own purposes or goals. Within the concept of positive freedom, the focus is on the self-realization and self-development of people (Kittay, 2007, 2011; Widdershoven, 2003). Following this point of view, application of restrictions in the current daily life of people with moderate ID may sometimes lead to more freedom for them in the future. However, considering application of restrictions requires careful decision-making in which support staff, relatives and people with moderate ID need to participate. In this dialogue, it has to be made clear in what sense the growth or development of people with moderate ID is stimulated when applying restrictions is considered. To clarify this with respect to some findings within this dissertation, restrictions in the intake of food e.g. may prevent people with moderate ID from becoming obese. Becoming obese increases the chance of getting sick or loss of freedom of movement (Jin, Agiovlasitis, & Yun, 2020). As such, the application of restrictions in food-intake may promote clients' freedom instead of reducing it. In addition, the reasoning of support staff with respect to restricting clients in the use of social media each day late at night seems reasonable when clients get exhausted as a result of late use of the iPad. It is a form of sensitivity to focus on the physical and mental health of the client in case the client's health deteriorates. Furthermore, restrictions in the use of social media to prevent people with moderate ID from sexual harm, also seem acceptable. In all, many examples can be given in which the applied restriction does not diminish the clients' freedom, but rather promotes it.

In study 2 is found that people with moderate ID who agree with restrictions often derive the justifications underlying this agreement from significant others such as support staff or relatives. In other words, possibly they are doing what they are told and possibly they even repeat the justifications mentioned by staff and relatives. Participating people with moderate ID seemed to internalize the norms and values of significant others. Bearing this in mind, is it still possible to speak of their own evaluation, or is it the evaluation of restrictions of their staff or relatives? This is a complicated matter. There may be doubts on the authenticity of the provided answers of the people with moderate ID, but it is also hard to say that the answers and underlying values of people with ID are therefore not their own, since all people derive their values from relevant others. No man is an island and we all listen to

people who are close to us. With respect to current research (study 2), the utmost is done to provide the interviewed people with ID the safety to answer open and honest to questions regarding the evaluation of restrictions. The participating people with ID were interviewed in their own living environment during three times a day (in the morning, in the early evening, and later in the evening), during which restrictions in a particular domain of daily life might occur, such as restrictions in hygiene in the morning, in receiving social visits in the early evening and restrictions in bedtime later in the evening. In this way, the interviews were held not only close in time and place, but also included the context of the living environment of the person with ID.

Paternalism

In the general introduction care ethicist Tronto is introduced. She is aware of the risk of paternalism in care settings. According to Tronto, "caregivers may see themselves as more capable of assessing the needs of care receivers than they do themselves" (1993, p.170). She stipulates that this risk may encompass that care receivers are infantilized, especially when the caregivers' duty is tied to the caring role. Therefore, the hierarchical element in the client–staff relation should not be underestimated, according to Tronto. In the first study, this kind of infantilization is exemplified in a support worker describing that the Dutch soccer team had to play an international game late in the evening, which a client of her definitely wanted to see. According to the support worker the game was too late for the client to watch. For this reason the support worker switched the television on around six o' clock in the evening when another international soccer team was playing. The support worker told her client it was the Dutch soccer team that was playing, because she felt sorry for the client. Although, it is understandable that the support worker wanted to protect the client from a lack of sleep, other solutions would be possible in this case. For instance, for once the client could be permitted to go late to bed and see the game. This case is different from earlier mentioned cases in which clients wanted

to use the I-Pad late at night on a regular basis. Another, less ideal solution would be to record the game and let the client watch the game the next day.

The danger of being paternalistic to people with moderate ID, is all the more a real danger, since the clients in our study seemed to derive their justifications for restrictions from their relatives and support staff as we stated above. In other words, what their relatives considered good for them, they also considered good for themselves. In study 2, an example of this is found in the case of a young man with moderate ID who was restricted in calling with his mother. Initiated by the mother herself and supported by support staff, he was only allowed to call her once a week for half an hour. The client said that this was okay, since his mother could not spend too much time with him. In his own words 'he talked to much' and his mother had other things to do which were important to her. Hence, the person with ID agreed with his restriction in phoning and could even justify this restriction. However, he did not speak of his own wishes, desires or needs.

To deal with paternalism, Tronto emphasizes 'that care needs to be relentlessly democratic in its disposition' (1993, p. 171). She calls care democratic when there is in caregiving a focus on the needs of the care-receivers and on a sound balance in the relation between caregivers and care-receivers without paternalism from the side of the caregivers. With regard to our research-topic, care can become more democratic by not only focusing on protection from alleged harm, but also on the needs and desires of care-receivers. To explore these needs, support staff have to focus on the perspective of the client besides their own perspective. Staff should be supporting client's decision-making in exploring what the client considers as important for his or her well-being instead of substitute client's decision-making (Dinerstein, 2012). Needs vary from one person to another, but also vary over a lifetime. Therefore, ongoing dialogue between clients, relatives and support staff about possible realization of these needs is desirable. This dialogue may sometimes be complicated, because support staff, people with moderate ID and their relatives may have different views on the application of restrictions. In dialogue a sound balance between the interests of people with moderate ID, relatives

and their relatives has to be found. In case relatives are in favor of applying restriction(s) to their family member with moderate ID against which the client him/herself showed protest, as we have seen in study 3, and support staff doubt the necessity of the application of restrictions or even disagree with the relatives' view, it should be the task of support staff to act as advocates for their clients.

Parochialism

For support staff it is important to enter in social and emotional ties with their clients (Van Heijst, 2011). They should be stimulated to listen to their clients, take them seriously, try to understand them, create time for them, and they should be stimulated to be trustworthy, open and honest. In case support staff act like this, they are evaluated positively by clients (Embregts, 2009). Awareness of and sensibility for the needs and desires for the care-receivers is required here (Meininger 2001; 2005; Van der Zande, Baart, & Vosman, 2013). In this respect, support staff mention that due to the MCD they became more aware of client's wishes and the impact of restrictions on the client, and the importance of examining possible reasons underlying a client's protest, such as the client's refusal to leave for the day care center. In this sense, MCD may limit the danger of paternalism, in which "caregivers see themselves as more capable of assessing the needs of care receivers than they do themselves" [Tronto, 1993, p. 170]. In addition, MCD may also limit the danger of parochialism. With parochialism Tronto (1993, p. 170) means that those who are involved in ongoing, continuing relationships like support staff are likely to see the caring relationships that they are engaged in, as the most important one. People who are into parochialism overestimate their own contribution to care, may act partial and do not see that the care receiver is connected to much more care givers. This may result in support staff acting individually and not taking into account views of other support staff. In this respect MCD might be an suitable instrument to prevent support staff from acting individually. In MCD in which all support staff of clients participate, different views on care and restricting are shared and a broader view may be developed. In general, MCD can be seen as a method to support the dialogical reflection process of

participants. Support staff state that by examining MCD they learn from others such as their colleagues (Stolper, Molewijk, & Widdershoven, 2016). They perceive a better mutual understanding of each other's perspectives and learn to see a moral difficult situation from different perspectives. According to support staff, MCD stimulates a broadening of thinking and a sense of connecting with the care receivers (Seekles, Widdershoven, Robben, Van Dalfsen, & Molewijk, 2016; Svantesson et al., 2013). Our studies on MCD confirm these findings.

Limitations

There are some limitations to be made with regard to this dissertation. First, the fact that we interviewed support staff, relatives and people with moderate ID from one care organization in the eastern part of the Netherlands can be considered as a limitation. Organizations providing care and support to people with ID are characterized by their own history and context. This might influence the interpretation and implementation of policies with regard to the application of restrictions. Therefore interviewing support staff and clients from other care organizations might lead to different results. A second limitation is that we have interviewed a small number of respondents. Within our respondent group, respondents were purposively sampled based on relevant characteristics such as age and gender (all respondent groups), education level (relatives), work-experience (professionals), and length of stay in this particular care organization (clients). Altogether, 15 support staff (study 1), eight clients and their eight key-workers (study 2), ten relatives (study 3) and twelve support staff, were interviewed (study 4). Therefore the findings of this study, as is the case in most qualitative studies (Verschuren & Doorewaard, 2010), cannot represent a greater amount of support staff, clients and relatives. This dissertation did not focus on frequency however, but on the exemplary character of the issues discussed. Strength of this approach is that the profound analysis of the in-depth interviews may provide valuable input for e.g. formulating hypotheses to be studies in larger, quantitative research. Next, limitations with respect to the two studies MCD should be mentioned. In these studies three

vignettes were presented to support staff of two teams. A limitation is that these vignettes in which the application of restrictions were described, did not originate from actual experiences in daily life care in the teams of respondents themselves, but were derived from earlier studies. Although these dilemmas were pilot-tested and were considered as well-known dilemmas by support staff in both teams, they were not compiled on concrete experiences with their own clients. As a consequence, the studies focused solely on the opinions and perspectives of support staff of what they might do in a given situation. Final limitation is that only MCD with support staff is performed. It had been valuable to include clients and their relatives in the MCD's, which would have possibly increased the awareness of the perspective of the other.

Implications for practice

All five studies focused on daily life restrictions in the care for people with moderate ID. These daily life restrictions reveal many similarities with restrictions mentioned in the Care and Coercion Act (2018), article 2.1., category h.: 'Applying measures to arrange the life of the person concerned in such a way that the person has to do or to stop something'. This category can be seen as a new category in relation to earlier legislation (BOPZ Act, 1994) and embodies a broad field of restrictions in daily life of people with ID, which is not described in detail in the Care and Coercion Act. Findings from our studies provide valuable information about what support staff, people with moderate ID and their relatives consider as daily life restrictions. To sum up, daily life restrictions are found in the domains 1) eating and drinking, 2) bedtimes, 3) hygiene, 4) means of communications, 5) social contacts. The Care and Coercion Act states that, in case clients protest, application of these restrictions (category h.) is only allowed in case of the threat of serious disadvantage (neglect, danger, harm, physical and mental deterioration) for people concerned. Restrictions are also allowed in case people concerned, i.c. people with moderate ID and their relatives in their role as representatives, agree with the application of restrictions. Findings from our studies show that people with moderate ID as well as their relatives in

their role as representatives tend to agree with the restrictions. They tend to state that restrictions contribute to their own well-being (clients) or the wellbeing of their family member with an ID (relatives). Restrictions are applied in their own interest and for their own good, according to these respondents. In addition, support staff, who have no legal say in this matter, are inclined to endorse this opinion. They tend to see it as good caregiving as we have seen in chapters 2, 5 and 6. Consequently, in case people with moderate ID and their relatives in their role as representatives tend to agree with the application of restrictions, these restrictions cannot be described as involuntary care. However, when their privacy or dignity is threatened, some people with moderate ID showed protest against the restrictions as we have seen in chapter 3. Furthermore, in case caregiving is not tailor-made for their family members with moderate ID, relatives may also show protest as we have seen in chapter 4. According to these respondents, adaption of restrictions is necessary in case where organizational or medical protocols lead to static, inflexible care. For further implementation of the Care and Coercion Act (article 2.1.h.) these findings provide valuable information with respect to 1) concrete daily life domains in which restrictions are applied, 2) experienced threat of their dignity and privacy as important cause for clients to protest to (a) restriction(s) and 3) care experienced as static and/or inflexible care as important cause for relatives to protest to restrictions applied in the daily care of their family member with moderate ID.

A second implication for practice is that our findings might provide a stimulus for support staff, relatives and people with moderate ID to engage in MCD about the application of restrictions. In contributing to opening the black box of MCD sessions, we might have provided support staff insight into this practical tool for them to engage in themselves. MCD partly promotes, such as other tools as an on-line webtool (Embregts, Habraken, Trompenaars, & Negenman, 2015; Wegingskader Onvrijwillige Zorg, 2020), support staff's sensitivity for the perspective toward the other. It is advisable that MCD is performed on a regular basis in care organizations. We do recommend to include people with ID themselves and their relatives in MCD sessions. In this way people with ID are taken serious and there is a possibility to a real dialogue (United Nations Chronicle, 2004). Third, our findings may

contribute to the formulation of qualitative criteria for dealing with daily life restrictions. These criteria may be complementary to already existing criteria formulated in the report 'Qualitative criteria for dealing with restrictions in the care for people with intellectual disabilities' (Abma et al., 2006). This report named the following criteria: 1) professionalism of support staff, 2) communication, 3) reflection on aims, effects and means, 4) care as a process and 5) adequate preconditions. These criteria are based on an extensive literature-review, interviews and focus groups. In all, the report provides a valuable, philosophical and theoretical basis for dealing with restrictions. Since current research collected empirical data on the perception and evaluation of support staff, people with moderate ID, and their relatives, criteria applicable to daily care practice are formulated, complementary to the theoretical criteria provided by Abma et al. (2006). In the following, these criteria are listed and briefly described.

1. *Knowledge of the client.*

Current research showed that support staff need to recognize the needs, wishes and desires of their clients. Part of their professional competencies must be their ability to interpret the conduct of their clients in such a way that they understand what their clients really want. They need to observe, listen to and discern what is relevant for their clients. In this way they heighten their sensitivity of the perspective of the client. In study 1, support staff emphasize that it is pivotal to have good knowledge of the client. Knowing the client means that support staff can assess what is important for him or her. Having knowledge of the client, may help support staff prioritize the needs and wants of the client. Exploring the needs of clients means thorough listening and observing the clients, since, as we know, clients with moderate ID are inclined to do what relatives or staff wants them to do. In studies 4 and 5 we have seen that MCD can help support staff develop this ability to recognize needs and wants of people with moderate ID.

2. *Communication*

Support staff need to communicate with their clients, on a verbal and non-verbal way. They have to attune to them and communicate on their level of understanding. An attitude of careful communication with people with moderate ID is pivotal, since they do have the tendency to adjust to the wishes of their relatives and support staff as we found in study 2. In this study, possible restrictions were examined by interviewing clients close in time and place in which restrictions might be applied. For instance, clients were asked in their own bedroom and in the early morning whether they experience any restrictions in the time they should wake up. This approach could be well adopted by support staff in identifying the needs and wishes of their clients.

3. *Proportionality, effectiveness, subsidiarity*

To evaluate the application of restrictions, the criteria proportionality, effectiveness and subsidiarity can be applied. This is in line with our conclusion in study 3 of this dissertation. In this chapter is stated that for a justified application of restrictions, these criteria can be helpful (Berghmans, 1992; Dörenberg, Embregts, Van Nieuwenhuijzen, & Frederiks, 2013). In using the criteria, the application of a restriction should be in proportion, should lead to the desired effect, and, finally, should be as less intrusive as possible for the person concerned.

4. *Dialogue between people with moderate ID, relatives and support staff*

When the application of restrictions in daily life of people with moderate ID is considered or evaluated, it is advisable to start a dialogue between support staff, clients and relatives. Promotion of the well-being of the client should be leading in this dialogue. Pivotal in this dialogue is that the perspective of the client is included. Subsequently, all different perspectives have to be weighted. The above

mentioned criteria proportionality, effectiveness and subsidiarity may be helpful when restrictions are evaluated or considered. In some cases, specialists such as an educational specialist or physician, have to be part of the dialogue.

Conclusion

Findings from the studies are coherent. Participating support staff as well as people with moderate ID and their relatives tend to agree with daily life restrictions in case they promote the client's well-being. In those cases, restrictions are considered as best-interest care. However, participants also experience difficulties with these restrictions. Support staff indicated to experience moral doubts in applying restrictions. People with moderate ID and their relatives are critical about restrictions when they violate their privacy or dignity (clients) or when restrictions are applied without flexibility (relatives). Additionally, relatives stipulate the importance of being involved in the process of arriving at and applying restrictions to their family members with a moderate ID. Since the evaluation of daily life restrictions appears nuanced, starting and maintaining a dialogue about the application of restrictions between support staff, relatives and clients themselves to achieve supported decision-making is crucial. In this dialogue it is pivotal to include the perspective of the client. For staff it is of the utmost importance to promote their sensitivity for the perspective of the client. In this respect, Moral Case Deliberation may be an appropriate means to engage in a joint discussion.

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Summary

Introduction

This dissertation focuses on restrictions in daily care for people with moderate intellectual disability (ID). Besides well-known restrictions, such as isolation and physical restriction, people with moderate ID also have to deal with 'mild' daily restrictions. Those restrictions concern social restrictions, such as restrictions in the use of social media, in hygienic settings, in deciding what and how much to eat or drink, or restrictions in bedtimes. These restrictions are commonly used in daily care and are often applied as collective measures to all people with ID living in the same house or living group. In this dissertation, we examine how people with moderate ID, their support staff, and their relatives perceive and evaluate these restrictions. An evaluation of these restrictions has to be seen in the light of paradigm shift in the care for people with ID in the last decades: from a focus on substituted decision-making to supported decision-making. In contrary to substituted decision-making in which another person decides for the person concerned, is supported decision-making based on the principle that all human beings are autonomous even if at some level support is needed. Since people with ID do not always possess the cognitive capacities and competencies to make responsible choices, they are, to a greater or lesser degree, to be supported in their decision-making. Partnership with significant others is needed to achieve supported decision-making. People with ID perceive their support staff and family members as these significant others. They are the natural partners of people with ID.

Following the paradigm-shift from substituted decision-making to supported decision-making for people with ID, the freedom for people with ID to make their own decisions is to be encouraged. As a consequence, there has been an emphasis on diminishing restrictions in the care for people with ID. In these care-settings, the focus is mostly on the diminishing of severe, often physical, restrictions such as isolation, enclosing, fixation, and obliged use of medicaments. These severe restrictions are often applied due to the challenging behaviors of people with ID. However, they are found intrusive for people with ID, and possibly reduce their well-being. In diminishing restrictions, less focus is on 'mild' restrictions, which are applied in the everyday life of people with ID. These daily life restrictions include

the obligation for people with ID to take a daily shower or restrictions in the intake of the amount of food. Which of these daily life restrictions are in the best interest for people with ID, and which restrictions diminish their well-being, is a moral issue.

In this dissertation, we are interested in what kind of restrictions are applied in the daily life of people with moderate ID. What kind of care in their daily life do people with moderate ID, their support staff, and their relatives experience and perceive as restricting? Instead of focusing on severe physical restrictions for people with challenging behavior, which is the case in most literature, this dissertation will focus on daily life care and what might be experienced as restricting in this. Next, we are interested in how support staff, people with moderate ID themselves, and their relatives perceive and evaluate these daily life restrictions and which justifications they use for the application of restrictions. Besides exploring what kind of restrictions might be applied on people with moderate ID and on what grounds, we are also interested in how support staff, people with moderate ID, and their relatives deal with the application of restrictions. Here, the question raises what kind of strategies support staff and relatives use to apply restrictions and how these strategies are perceived and experienced by people with moderate ID? In all, the central research question of this dissertation is: **how do support staff, people with moderate ID themselves, and relatives of people with moderate ID perceive and evaluate restrictions in the daily life of people with moderate ID?**

Providing an answer to this question is relevant for the following reasons: a) few research is done on the evaluation of daily life restrictions applied to people with moderate ID, in contrast to people with mild ID, and; b) daily life restrictions are not often recognized as restrictions, since they are common in the life of people with moderate ID. Daily life restrictions may be seen as pedagogical measures instead of as restrictions. They may also be perceived as 'mild' in contrast to severe physical restrictions, such as fixation or isolation.

Furthermore, the application of daily life restrictions in the care for people with ID may also have legal implications. According to the Dutch Care and Coercion Act, 'measures to arrange the life of the person

concerned in such a way that the person has to do or to stop something, including the use of means of communication' (article 2.1. h.) are only allowed in cases of threats towards severely disadvantaged people, or in cases where the person with ID or his or her representative agrees with the restriction.

Therefore, the **aim** of this dissertation is twofold. First, by exploring the view of support staff, relatives, and clients on daily life restrictions for people with moderate ID, we intend to provide insight in the evaluation of these restrictions. Three studies with an explorative character, described in chapters 2 through 4, are focused on this topic. Second, our aim is to promote awareness among support staff for the client-perspective in cases where restrictions are applied. Awareness and sensitivity for the perspective of the client may contribute to more supported decision-making. In this dissertation, the focus will be on people with moderate ID. These people with ID (IQ 35/40 – 50/55) require ongoing assistance for conceptual tasks and decision-making. Deficits in intellectual functions, such as reasoning, problem-solving, planning, abstract thinking, and judgment, are combined with deficits in adaptive functioning that results in a failure to meet personal independence. People with moderate ID are therefore less able to express their own wishes and needs than people with mild ID. They are also more dependent on significant others, like support staff and relatives, than people with mild ID. On the other hand, they possess more cognition, abilities, and verbal capabilities than people with severe ID.

In this dissertation, an ethics of care is the leading orientation. In an ethics of care, the uniqueness of every single situation and context and the inter-related character of human life is emphasized. It stresses the importance of relationships and compassionate care between people. Essential values for building up these relationships are responsibility, care, and involvement. With respect to care in organizations, this means that for support staff an attitude of professional loving care is desired. Moral values like attentiveness, commitment, and sensibility are highly valued in this respect.

Finally, all respondents in this research are living in (clients) or working in (support staff) or affiliated with (relatives) care-organization Elver, an organization for people with intellectual disability in the eastern part of the Netherlands.

Chapter 2 – Study 1

In the first study, we examined support staffs' evaluations on the restrictions of people with moderate ID. Our research question was: What do support staff consider as restrictions and how do they justify these restrictions? In this study, data were collected by semi-structured interviews.

We found that most restrictions were centered around the basic elements in the life of the client. We identified the next domains: eating/drinking, daily structure, hygiene, means of communications, relations, and bedtimes. In justifying the restrictions, support staff said that it was necessary to give clarity in what clients are supposed to do, to structure their life, to provide them rest, to keep them in good physical health, and to keep them from danger. However, support staff also showed moral doubt. Although they chose to restrict, they were not always sure whether the application of restrictions provided good care for their clients. Subsequently, to get the restrictions accepted when support staff chose to restrict, they used different strategies from communicating with the client to nudging the client. The following strategies were found: A) *Communicate with the client.* Support staff stated that starting a process of communication with the client can lead to better acceptance of the daily life restriction. They are willing to explain the situation to the clients, telling their clients why it is good for them that there are restrictions. B) *Know the client.* A good relation with the client is of great value, according to support staff. Knowledge of the client and having a bond with him or her can result in a client's acceptance of the restriction. C) *Nudge the client.* In situations where there seems no alternative to the restriction, support staff sometimes use the method of nudging. Nudging is a way to lead clients to a certain goal. D) K*eep a distance from the client.* Another way of dealing with restrictions is remaining at a distance from the situation. Support staff tell their clients what needs to

be done, but they don't push them to do it; they remain at a certain distance until the clients do what they are told to do. E) *Confront the client.* In other situations, support staff choose confrontation with their clients. They want to make a point clear and they continue with their action until the client has done what they want him or her to do. F) *Hide restrictions.* Camouflaging the daily life restriction is another method used by support staff to deal with restricting. E.g. clients who overeat receive a small portion twice, or the meal is spread out on the plate in such a way that the amount of food seems to be more.

Chapter 3 – Study 2

In chapter 3, we examine the perception and evaluation people with moderate ID have on their restrictions. When restrictions are applied, they must be in the interest of people with ID. Therefore, it is essential to examine the perception and evaluation of those being restricted. This study examines how people with moderate ID themselves, perceive and evaluate restrictions in daily care. Based on an extensive pilot study, we conducted interviews so that they were close in time and location towards areas where possible restrictions might occur. We interviewed eight people with moderate ID three times a day: in the morning after getting up, in the early evening, and in the late evening. We asked the participating clients how they experienced daily care and how they perceived the applied restrictions. Additionally, we applied a triangulation of sources. After conducting interviews with eight people with moderate ID, we examined their clinical files on the description of restrictions and interviewed their key workers. Findings indicate that respondents tend to consider the applied restrictions to be beneficial for themselves and also for others. In this respect, the following justifications are primarily mentioned: a) promoting their own physical and mental health, e.g., restrictions regarding drinking and eating; b) promoting their safety, e.g., restrictions in using a mobile phone to keep people with ID from questionable contacts; c) obtaining structure and rest, e.g., restrictions regarding fixed bedtimes. In addition, data indicates that the justifications mentioned by

respondents might be derived from justifications provided by significant others, like family members. People with ID explicitly refer to these significant others in mentioning the justifications for the applied restrictions.

Furthermore, results demonstrate communality between the participating people with ID and their key workers in the perception and evaluation of restrictions. In other words, people with ID tend to comply with the applied restrictions. When the participants with ID and their key workers differ in their evaluation of applied restrictions, there appears to be a value-based dissensus. People with moderate ID emphasize the importance of their privacy and dignity, whereas support staff focus on their physical health as a justification for the applied restriction. In this sense, traditional care values, like causing no harm and beneficence, seem to oppose other, more person-centered values, like respecting a person's privacy and dignity. Therefore, it is advisable that support staff also develop moral sensitivity for these personal values.

Chapter 4 – Study 3

In addition to the perspective of support staff and people with ID themselves, the view of relatives of people with moderate ID on daily life restrictions should also be examined. Therefore, we evaluated ten relatives on their views towards restrictions in daily care for their family members. In their evaluation, all respondents stipulate that the application of restrictions may be necessary to promote the well-being of their family members. Respondents state that due to their intellectual disability, their family members may lack the awareness and judgment of what is the best thing to do or what is in their best interest. In this respect, restrictions can be helpful to guide their family members with moderate ID in the 'right direction.' The following justifications for applying restrictions were discerned. Respondents endorse restrictions if they promote: 1) the physical well-being, 2) the safety, and 3) a 'normal,' indistinctive appearance of their family members. Although all respondents stipulate the importance of applying restrictions to their family members with moderate ID, two styles of

application were identified. Some of the respondents indicate that restrictions just have to be followed in all cases, even when their family members with moderate ID might wish to alter these restrictions. We call this the *'rules are rules' style*. In cases when their family members protest, these respondents seek ways to maintain the restrictions. Analysis showed four strategies: 1) explaining the background of the restriction and mentioning the negative consequences if their family member does not follow the restrictions, 2) offering two alternatives that are perceived as acceptable by the respondent, 3) using an argument of a competent authority to persuade their family member, and 4) being firm in adhering to the restrictions without adapting them. Other respondents focused on the dialogue between support staff, their family members with ID, and relatives. They mention that in some cases, restrictions must be adapted. We call this the 'tailor-made' style. According to these respondents, adaption of restrictions is desirable in cases where organizational or medical protocols lead to static, inflexible care. Respondents stipulate that in these cases, they want to have a say in the rulemaking process and in the application of restrictions. Not the prescribed protocol, but the interest of their family member with ID should be the guide. These respondents want to be involved in the care of their family member. The desired dialogue between support staff, relatives, and family members with moderate ID should result in tailor-made rules for their family members with moderate ID. Instead of fixed restrictions or protocols for all clients, these respondents prefer personalized restrictions, which requires a certain form of flexibility from support staff and the care organization.

Chapter 5 – Study 4

In contributing to the well-being of people with moderate ID, it is important to promote the support staff's sensitivity to the perspective of people with moderate ID themselves, noting any potential signs of protest against restrictions. Moreover, the care exhibited when a person with ID shows protest or resistance, even when the signs are subtle, can be perceived as involuntary care according to the Dutch Care and Coercion Act. Applying daily life restrictions can be part of providing good care, but only

insofar as these restrictions are in the best interests of people with ID and are decided upon in dialogue with them.

To promote the desired sensitivity and awareness of the perspective of 'the other,' which is considered a relevant moral competency, moral case deliberation (MCD) might be an appropriate method. MCD can be defined as the methodological reflection on concrete moral cases among health care professionals. By examining what is morally right in a specific care situation, MCD contributes to the improvement of the ethical climate and the moral quality of the care process.

In this study, two teams of support staff, which support people with (moderate) ID, participated in this research. The first team, which supports eight clients with moderate ID, consists of six support staff who all participated in this research; the second team, which supports 11 clients with moderate ID, consists of eight support staff of which six support staff participated in the research. MCD was held under both teams with respect to three vignettes, which were probed in a pilot-study. In the description of the first vignette, the client has to stop an activity, e.g., switching off his iPad after 10.00 P.M. The client is disappointed about this restriction being applied by support staff and wants to decide for himself at what time he stops using his iPad. In the second vignette, a client is physically forced to go to the day-centre. She does not want to go and tells support staff that she wants to stay at home. The client does not give an explicit reason for her refusal. Support staff believe that the client has to go to her work however and force her to go by pulling her arms. In the third vignette, a client wants to start an activity (making a phone call to his mother) but is prohibited from doing so. The mother of the client has difficulties with these telephone calls since there seems to be no end to the stories of her son. Therefore, the mother has decided that her son is only permitted to phone her for half an hour a week.

All participating support staff were interviewed individually in advance of the MCD sessions, as well as after the completion of the three MCD sessions. In these interviews, the central question was what interviewees would describe as good care in the presented vignettes. The interviews were semi-

structured and lasted approximately half an hour. In this study, our aim was to examine the extent to which MCD leads to changes in the perspectives of support staff with regard to daily life restrictions applied to people with moderate ID. In exploring this, we identified that respondents tend to evaluate the vignettes in the same way prior to and following MCD. Respondents maintained the perspective that sticking to the restrictions is considered to be in the best interest of a client. Both prior to and following the MCD, this view to restrict clients to provide them with structure, clarity, and rest remained dominant. However, some respondents changed their perspective from a focus on sticking to the restrictions, to a focus on adapting the restrictions to provide more freedom for the client. Following MCD, these respondents stipulate that they are more aware of the impact restrictions may have on a client, especially in cases where physical force is applied, as described in the vignette of the client who was physically forced to go to her work. In this respect, MCD can be seen as a method to promote the quality of the care process and as a key to promote more attentiveness towards the viewpoint of 'the other.' It is also clear that more is needed than incidentally performing MCD. Potentially, MCD should occur on a regular basis, but multidisciplinary discussions among support staff and other professionals about the necessity of restrictions may also lead to more sensitivity and awareness among support staff.

Chapter 6 – Study 5

Moral case deliberation (MCD) might be used as an instrument for a team of support staff to jointly reflect on these dilemmas and might be considered as a form of ethical support as we have seen in the previous chapter. However, regarding the actual content of MCD, little research has been conducted. The few studies that have been performed tended to focus on the participants' perception and evaluation of MCD. Most studies do not focus on the actual themes discussed within the moral deliberations, nor on the underlying motives and outcomes of decision-making. MCD may even be seen as a 'black box' for the non-participant. Therefore, there is a need to capture the content beyond

moral reasoning within MCD. As such, we have conducted MCDs among support staff and additionally analyzed the content of the MCDs to open this 'black box.' The three vignettes presented in the previous chapter (vignette iPad, vignette day care centre, and vignette phone-rule) were the discussed topics within the MCDs. Amongst the variety of methods to conduct MCD, we used the dilemma-method, which is a structured and frequently used form of moral deliberating in health care. In this method, participants discuss an ethical dilemma and are supported by an MCD-facilitator. The task of the MCD-facilitator is to structure and clarify the dialogue, thereby supporting the participants in phrasing the moral dilemma.

Outcomes were the following. In the vignette of the iPad, both teams decided to provide the client with more freedom to use his iPad after 10.00 P.M. However, this freedom would not be unconditional. If participants noticed serious sleep deprivation or a deterioration of the client's physical condition, they would revert to the restriction to switch off the iPad after 10.00 P.M. In the vignette of the day care centre, both teams chose to persuade the client to go to the day care centre. However, they would not physically force the client. Instead, participants would contact the family of the client and support staff at the day centre to explore a possible motive underlying the client's refusal to go to the day centre. In the vignette of the phone-rule, participants in the first team decided to support the wish of the client to have more contact with his mother. They would be willing to contact the mother or other family members to explore the possibilities of broadening telephone contact between the client and his mother. The second team decided to stick to the restriction in order not to disturb the relationship between the client and their mother. According to this team, maintaining a good relationship between the mother and the client is in the client's best interests.

Conclusion

The findings from the studies are coherent. Participating support staff as well as people with moderate ID and their relatives tend to agree with daily life restrictions in cases where they promote the client's

well-being. In those cases, restrictions are considered as best-interest care. However, participants also experience difficulties with these restrictions. Support staff indicated experiences of moral doubt in applying restrictions. People with moderate ID and their relatives are critical about restrictions when they violate their privacy or dignity (clients), or when restrictions are applied without flexibility (relatives). Additionally, relatives stipulate the importance of being involved in the process of arriving at and applying restrictions to their family members with moderate ID. Since the evaluation of daily life restrictions appears nuanced, starting and maintaining a dialogue about the application of restrictions between support staff, relatives, and the clients themselves to achieve supported decision-making is crucial. In this dialogue, it is pivotal to include the perspective of the client. For staff, it is of the utmost importance to promote their sensitivity for the perspective of the client. In this respect, Moral Case Deliberation may be an appropriate means to engage in a joint discussion.

Samenvatting

Inleiding

In dit proefschrift is onderzoek verricht naar perceptie en waardering van beperkingen in de dagelijkse zorg voor mensen met een matige verstandelijke beperking. Naast fysiek ingrijpende vrijheidsbeperkingen, zoals afzondering en beperkingen in de bewegingsvrijheid hebben mensen met een matige verstandelijke beperking van doen met minder ingrijpende beperkingen in hun dagelijkse leven. Deze beperkingen betreffen bijvoorbeeld restricties in het gebruik van sociale media, restricties op hygiënisch vlak, restricties in type en hoeveelheid eten of drinken, of restricties in bedtijden. Dit soort beperkingen wordt in de dagelijkse zorg regelmatig toegepast als collectieve maatregel voor alle mensen met een verstandelijke beperking die in hetzelfde huis of in dezelfde woongroep wonen. In dit proefschrift is onderzocht hoe mensen met een matige verstandelijke beperking, hun begeleiders en hun verwanten deze beperkingen in de dagelijkse zorg ervaren en waarderen. Hun perceptie en waardering van deze beperkingen moet worden gezien in het licht van een verschuiving in paradigma in de zorg voor mensen met een verstandelijke beperking. In de laatste decennia is er namelijk een verschuiving gaande van een nadruk op vervangende besluitvorming (substituted decision-making) naar een nadruk op gezamenlijke besluitvorming (supported decision-making). In tegenstelling tot vervangende besluitvorming, waarin anderen besluiten voor mensen met een verstandelijke beperking, is gezamenlijke besluitvorming gebaseerd op het principe dat mensen autonome wezens zijn ook al hebben ze een bepaalde mate van ondersteuning nodig. Omdat mensen met een verstandelijke beperking niet altijd de cognitieve capaciteiten en competenties bezitten om verantwoorde keuzes te maken, moeten zij in meerdere of mindere mate worden begeleid in het proces van besluitvorming. Voor mensen met een matige verstandelijke beperking is ondersteuning door 'significante anderen' belangrijk om tot gezamenlijke besluitvorming te komen. Mensen met een verstandelijke beperking beschouwen hun begeleiders en verwanten vaak als deze 'significante anderen'. Zij zijn als het ware de natuurlijke partners van mensen met een verstandelijke beperking.

Door de toenemende aandacht voor gezamenlijke besluitvorming in plaats van vervangende besluitvorming, lijkt de keuzevrijheid van mensen met een verstandelijke beperking te zijn vergroot. Als gevolg hiervan is er nadruk komen te liggen op het afbouwen van beperkingen in de zorg voor mensen met een verstandelijke beperking. In de praktijk van de zorg ligt hierbij de nadruk vaak op het afbouwen van 'zware', fysiek-ingrijpende beperkingen zoals afzondering, insluiting, fixatie en het verplicht innemen van medicijnen. Deze beperkingen worden vaak toegepast als reactie op grensoverschrijdend gedrag door mensen met een verstandelijke beperking. Door mensen met een verstandelijke beperking zelf alsook door hun begeleiders en verwanten worden ze echter als ingrijpend ervaren. Deze 'zware' beperkingen kunnen het welzijn van mensen met een verstandelijke beperking aantasten. Bij de afbouw van beperkingen is er in tegenstelling tot de ingrijpende, fysieke beperkingen, minder aandacht voor 'milde' beperkingen die in het dagelijks leven van mensen met een verstandelijke beperking worden toegepast. Deze alledaagse beperkingen komen echter wel veel voor in het leven van mensen met een verstandelijke beperking. Alledaagse beperkingen zijn bijvoorbeeld de verplichting voor mensen met een verstandelijke beperking om dagelijks te douchen, of het gaat om beperkingen in de inname van de 'hoeveelheid' voedsel. Welke van deze beperkingen in het dagelijks leven in het belang zijn voor mensen met een verstandelijke beperking en welke beperkingen hun welzijn juist aantasten, is een vraag van morele aard.

In dit proefschrift is daarom onderzocht wat voor soort beperkingen er worden toegepast in het dagelijks leven van mensen met een matige verstandelijke beperking. Ook wordt onderzocht hoe begeleiders, mensen met een matige verstandelijke beperking zelf en hun verwanten deze beperkingen in het dagelijks leven ervaren en waarderen en welke rechtvaardigingen zij benoemen voor het eventueel toepassen van beperkingen. Vervolgens is onderwerp van onderzoek op welke manier begeleiders, mensen met een matige verstandelijke beperking en hun verwanten omgaan met beperkingen. Als er voor wordt gekozen om te beperken, welke strategieën gebruiken begeleiders en verwanten om deze beperkingen toe te passen en hoe worden deze strategieën door mensen met een matige verstandelijke beperking ervaren. Samengevat is de centrale onderzoeksvraag van dit

proefschrift: **hoe ervaren en waarderen begeleiders, mensen met een matige verstandelijke beperking zelf en hun verwanten beperkingen in het dagelijks leven van mensen met een matige verstandelijke beperking?**

Het beantwoorden van deze onderzoeksvraag is relevant, aangezien a) er weinig onderzoek is gedaan naar waardering van beperkingen in de zorg voor mensen met een matige verstandelijke beperking in tegenstelling tot mensen met een lichte verstandelijke beperking, b) beperkingen in het dagelijks leven vaak niet worden beschouwd als beperkingen, omdat ze gemeengoed zijn in het leven van mensen met een matige verstandelijke beperking. Beperkingen in het dagelijks leven van cliënten worden soms geduid als pedagogische maatregelen in plaats van als beperkingen. Ook kunnen ze worden gezien als 'mild' in tegenstelling tot 'zware', lichamelijke beperkingen, zoals fixatie of isolatie.

De toepassing van beperkingen in het dagelijks leven in de zorg voor mensen met een verstandelijke beperking heeft tevens juridische implicaties. Volgens de Wet Zorg en Dwang zijn 'maatregelen om het leven van de betrokkene zodanig in te richten dat de betrokkene iets moet doen of laten, waaronder het gebruik van communicatiemiddelen' (artikel 2.1. h.) alleen toegestaan in geval van dreigend ernstig nadeel voor de betrokkenen of indien de persoon met een verstandelijke beperking of zijn of haar vertegenwoordiger instemt met de beperking.

Het doel van dit proefschrift is tweeledig. Ten eerste wil dit proefschrift inzicht bieden in de manier waarop begeleiders, mensen met een verstandelijke beperking zelf en hun verwanten deze beperkingen waarderen. De eerste drie studies met een exploratief karakter, beschreven in hoofdstuk 2 tot en met 4, behandelen dit thema. Ten tweede wil dit proefschrift de bewustwording van begeleiders voor het cliëntperspectief bevorderen bij eventuele toepassing van beperkingen. Bewustwording en sensitiviteit voor het perspectief van de cliënt kan namelijk leiden tot meer verdieping van het proces van gezamenlijke besluitvorming (supported decision-making).

In dit proefschrift staan mensen met een matige verstandelijke beperking centraal. Mensen met een matige verstandelijke beperking (IQ 35/40 - 50/55) hebben behoefte aan ondersteuning bij conceptuele taken en besluitvorming. Beperkingen in intellectuele functies, zoals redeneren, probleemoplossing, planning, abstract denken en oordeelsvorming samen met beperkingen in adaptief functioneren, resulteren bij hen in een beperkte mate van onafhankelijkheid. Mensen met een matige verstandelijke beperking zijn daarnaast minder goed in staat om hun eigen wensen en behoeften te articuleren dan mensen met een licht verstandelijke beperking. Ook zijn zij meer afhankelijk van belangrijke anderen zoals begeleiders en verwanten dan mensen met een lichte verstandelijke beperking. In vergelijking met mensen met een ernstige verstandelijke beperking beschikken ze echter over grotere cognitieve vaardigheden en verbale capaciteiten.

In dit proefschrift zullen wij elementen uit de zorgethiek inbrengen. In de zorgethiek wordt het unieke karakter van elke situatie en elke context almede het relationele karakter van het menselijk leven benadrukt. Zorgethiek benadrukt het belang van betekenisvolle relaties tussen mensen onderling. Essentiële waarden voor het opbouwen van deze betekenisvolle relaties zijn verantwoordelijkheid, zorg en betrokkenheid op elkaar. Dit betekent dat in de context van de zorg vanuit de zorgverlener een houding van menslievende zorg is gewenst. Morele waarden als aandacht, betrokkenheid en sensitiviteit zijn kernwaarden binnen deze oriëntatie.

Tot slot, respondenten binnen dit onderzoek zijn woonachtig (cliënten) of werkzaam bij (begeleiders) of geaffilieerd met (verwanten) zorginstelling Elver, een organisatie voor mensen met een verstandelijke beperking in het oosten van het land.

Hoofdstuk 2 – Studie 1

In de eerste studie is onder begeleiders onderzoek gedaan naar hun beleving en waardering van dagelijkse beperkingen toegepast in de zorg voor mensen met een matige verstandelijke beperking. De onderzoeksvraag was: Wat beschouwen begeleiders als beperkingen in het dagelijks leven van

mensen met een matige verstandelijke beperking en hoe rechtvaardigen zij deze beperkingen? In deze studie werden gegevens verzameld door middel van semigestructureerde interviews onder 15 respondenten. We identificeerden de volgende domeinen waarin beperkingen werden toegepast: eten/drinken, dag-structuur, hygiëne, communicatiemiddelen, sociale contacten en bedtijden. Begeleiders rechtvaardigden de beperkingen door te benoemen dat het nodig is om cliënten duidelijkheid te geven, hun leven te structureren, hen rust te geven, hen in goede fysieke gezondheid te houden en hen te behoeden voor gevaarlijke situaties. Begeleiders verwoordden echter ook morele twijfel: hoewel ze ervoor kozen om beperkingen toe te passen, waren ze er niet altijd zeker van of de toepassing van deze beperkingen wel goede zorg voor hun cliënten betekende. Om beperkingen die begeleiders noodzakelijk achtten geaccepteerd te krijgen, gebruikten begeleiders verschillende strategieën: a) communiceren met de cliënt. Begeleiders stellen dat het op gang brengen van een proces van communicatie met de cliënt kan leiden tot acceptatie van de beperking; b) de cliënt leren kennen. Kennis van de cliënt en het aangaan van een band met hem of haar kan leiden tot snellere acceptatie van de beperkingen; c) nudging. In situaties waarin er geen alternatief lijkt te zijn voor de beperking, maken begeleiders soms gebruik van 'nudging', een manier om cliënten op subtiele wijze naar een bepaald doel te leiden; d) afstand houden van de cliënt. Een andere manier om met beperkingen om te gaan is op afstand te blijven. Begeleiders vertellen hun cliënten wat er moet gebeuren, maar ze dwingen hen niet om het te doen, ze blijven op een bepaalde afstand, totdat de cliënt datgene gaat doen wat de begeleiders wensen; e) de confrontatie met de cliënt aangaan. In andere situaties kiezen begeleiders ervoor de confrontatie met de cliënt aan te gaan. Ze willen een punt duidelijk maken en ze volharden totdat de cliënt heeft gedaan wat ze willen dat hij of zij doet, f) beperkingen camoufleren. Het verbergen van beperkingen is een andere methode die begeleiders gebruiken om met beperkingen om te gaan. Bijvoorbeeld, cliënten die meer willen eten dan goed voor hen is, krijgen twee keer een kleine portie opgeschept of de maaltijd wordt zo op het bord uitgespreid dat de hoeveelheid voedsel meer lijkt te zijn dan het in feite is.

Hoofdstuk 3 – Studie 2

In hoofdstuk 3 is de perceptie en waardering van beperkingen door mensen met een matige verstandelijke beperking zelf onderzocht. Als beperkingen worden toegepast, dan moeten zij in het belang van mensen met een verstandelijke beperking zijn. Daarom is het essentieel om hun eigen perceptie en waardering te onderzoeken. Na een uitgebreide pilotstudie hebben we onder acht mensen met een matige verstandelijke beperking interviews afgenomen. Deze interviews vonden plaats dicht op het moment en in de fysieke ruimte waarin de betreffende beperkingen zouden kunnen worden toegepast. Zo hebben we hen gedurende drie momenten op de dag geïnterviewd: 's ochtends na het opstaan, in het begin van de avond en in de late avond. We vroegen de deelnemende cliënten hoe zij de dagelijkse zorg ervaren, of er beperkingen worden toegepast en zo ja, hoe zij deze ervaren. Daarnaast pasten we triangulatie van bronnen toe door het analyseren van hun zorgplannen op beschrijvingen van mogelijke beperkingen en door de afname van interviews met hun persoonlijke begeleiders. De bevindingen toonden aan dat cliënten geneigd zijn de toegepaste beperkingen te beschouwen als bevorderlijk voor hun eigen welzijn en dat van anderen. In dit verband werden de volgende redenen genoemd. Volgens de deelnemende cliënten kunnen beperkingen a) hun eigen lichamelijke en geestelijke gezondheid bevorderen, bijvoorbeeld beperkingen met betrekking tot de hoeveelheid drinken en eten, b) hun veiligheid bevorderen, bijvoorbeeld beperkingen met betrekking tot het gebruik van een mobiele telefoon om hen te beschermen tegen risicovolle contacten met anderen, c) structuur en rust bevorderen, bijvoorbeeld beperkingen met betrekking tot vaste bedtijden, zodat zij voldoende nachtrust krijgen. De door de cliënten genoemde motiveringen lijken te zijn ontleend aan motiveringen die door anderen, zoals hun verwanten of begeleiders, zijn gegeven. Personen met een verstandelijke beperking verwijzen expliciet naar deze voor hun belangrijke anderen bij het noemen van de redenen voor de toegepaste beperkingen.

Een andere uitkomst van het onderzoek is dat de deelnemende cliënten en hun persoonlijk begeleiders in hun perceptie en waardering van de beperkingen, een gelijkluidende visie bezitten. Wanneer de cliënten en hun persoonlijk begeleiders wel verschillen in hun waardering van de

toegepaste beperkingen, lijkt dit een op waarden gebaseerde dissensus. Cliënten zelf benadrukken in dit verband het belang van hun privacy en waardigheid, terwijl begeleiders uitgaan van de fysieke gezondheid van cliënten als motivatie voor de beperking. In deze zin lijken traditionele zorgwaarden zoals 'goeddoen' te contrasteren met andere, meer persoonsgerichte waarden zoals het respecteren van de privacy en waardigheid van het individu. Het is raadzaam dat begeleiders morele sensitiviteit ontwikkelen voor deze persoonsgerichte waarden.

Hoofdstuk 4 – Studie 3

Naast het perspectief van begeleiders en mensen met een verstandelijke beperking zelf, is het ook van belang dat de visie van verwanten op beperkingen wordt onderzocht. Daarom hebben we in deze derde studie onderzocht hoe tien verwanten van mensen met een matige verstandelijke beperking, de beperkingen in de dagelijkse zorg voor hun naaste waarderen. In hun waardering van beperkingen stellen alle tien verwanten dat de toepassing van beperkingen noodzakelijk kan zijn om het welzijn van hun naasten te bevorderen. De respondenten (verwanten) geven aan dat hun naasten door hun verstandelijke beperking mogelijk niet goed weten wat het beste is in sommige situaties of wat in hun eigen belang is. In dit opzicht kunnen toegepaste beperkingen noodzakelijk zijn om hun naasten met een verstandelijke beperking in de "juiste richting" te sturen. De volgende door verwanten benoemde redenen voor het toepassen van beperkingen werden onderscheiden. Verwanten onderschrijven beperkingen als ze 1) het fysieke welzijn, 2) de veiligheid en 3) een 'normaal' uiterlijk van hun naasten, bevorderen. Hoewel alle verwanten het belang van het toepassen van beperkingen op hun naasten benadrukken, kunnen er twee manieren van toepassing van beperkingen worden onderscheiden. Sommige verwanten geven aan dat beperkingen in alle gevallen gevolgd moeten worden, ook als hun naasten moeite hebben met deze beperkingen. We noemen dit de "regels zijn regels"-stijl. In situaties waarin hun naasten met verstandelijke beperking protesteren, zijn deze verwanten geneigd te zoeken naar manieren om de beperkingen te handhaven. Uit analyse blijkt dat er vier strategieën zijn: 1) het

toelichten van de achtergrond van de beperking en het benoemen van de negatieve gevolgen indien hun naaste met verstandelijke beperking de beperkingen niet opvolgt, 2) het aanbieden van twee alternatieven die door de verwanten beide als aanvaardbaar worden beschouwd, 3) het gebruiken van een argument van een bevoegde autoriteit om hun naaste te overtuigen, 4) strak vasthouden aan de beperkingen zonder deze aan te passen.

Andere respondenten onder de tien verwanten richtten zich daarentegen op de dialoog tussen begeleiders, verwanten en cliënten. Zij benoemen dat in sommige gevallen de beperkingen moeten worden aangepast. Dit noemen we de 'op maat gesneden stijl' ('tailor-made style'). Volgens deze verwanten is aanpassing wenselijk in situaties waarin organisatorische of medische protocollen leiden tot statische, inflexibele zorg. Deze verwanten geven aan dat zij in deze situaties inspraak willen hebben in het proces van toepassing van restricties. Niet het voorgeschreven protocol, maar het belang van hun naaste moet uitgangspunt zijn. Deze groep verwanten wil betrokken worden bij de zorg voor hun naaste. De gewenste dialoog tussen begeleiders, verwanten en cliënten moet leiden tot regels op maat voor hun naasten. In plaats van beperkingen of protocollen voor alle cliënten geven deze verwanten de voorkeur aan op de persoon toegepaste beperkingen, wat een bepaalde vorm van flexibiliteit van begeleiders en de zorgorganisatie vereist.

Hoofdstuk 5 – Studie 4

Bij het leveren van een bijdrage aan het welzijn van mensen met een matige verstandelijke beperking is het belangrijk om de sensitiviteit te bevorderen van begeleiders voor het perspectief van mensen met een matige verstandelijke beperking en hun mogelijke weerstand tegen beperkingen. Zorg waartegen een persoon met een verstandelijke beperking weerstand vertoont, zelfs als de tekenen subtiel zijn, kan volgens de Wet Zorg en Dwang als onvrijwillige zorg worden beschouwd. Het toepassen van beperkingen in het dagelijks leven kan weliswaar onderdeel zijn van het verlenen van goede zorg, maar alleen voor zover deze beperkingen in het belang zijn van mensen met een

verstandelijke beperking en in overleg met hen worden bepaald en toegepast. Sensitiviteit en bewustwording voor het perspectief van cliënten worden als een relevante morele competenties voor begeleiders beschouwd. We hebben onderzocht of de toepassing van moreel beraad een geschikt middel is om deze competenties te bevorderen. Moreel beraad is een methodologische reflectie op morele dilemma's. Door gezamenlijk te analyseren wat in een specifieke zorgsituatie als moreel juist wordt ervaren, draagt moreel beraad bij aan de verbetering van het ethisch klimaat en de morele kwaliteit van het zorgproces.

In deze studie hebben twee teams van begeleiders deelgenomen aan dit onderzoek. Het eerste team, dat acht cliënten met een matige verstandelijke beperking begeleidt, bestaat uit zes begeleiders die allemaal aan het onderzoek hebben deelgenomen; het tweede team, dat elf cliënten met een matige verstandelijke beperking begeleidt, bestaat uit acht begeleiders van wie zes aan het onderzoek hebben deelgenomen. Bij ieder team werden drie moreel beraden georganiseerd. In ieder moreel beraad stond een vignet centraal, waarin herkenbare beperkingen in de dagelijkse zorg aan mensen met een matige verstandelijke beperkingen werden besproken. In het eerste vignet is beschreven dat een cliënt van de begeleiding na 22.00 uur zijn IPad moet uitzetten. De cliënt in dit vignet is echter teleurgesteld dat hij in zijn IPad gebruik wordt beperkt en wil zelf beslissen op welk moment hij stopt met het gebruik van zijn iPad. In het tweede vignet wordt een cliënt fysiek gedwongen naar de dagbesteding te gaan. De cliënt weigert en vertelt haar begeleiders dat ze thuis wil blijven. De cliënt geeft echter geen expliciete reden voor haar weigering. Haar begeleiders vinden dat de cliënt wel naar de dagbesteding moet gaan en dwingen haar door haar fysiek beet te pakken en mee te nemen. In het derde vignet wil een cliënt telefoneren met zijn moeder, maar dat is niet toegestaan. De moeder van de cliënt heeft moeite met de telefoontjes van haar zoon, omdat er geen einde lijkt te komen aan zijn verhalen. Daarom heeft moeder besloten dat haar zoon slechts een half uur per week met haar mag bellen. De begeleiding gaat hier in mee.

Alle deelnemende begeleiders zijn zowel voorafgaand aan de moreel beraad sessies als na afloop individueel geïnterviewd. In deze interviews stond de vraag centraal wat de geïnterviewden in het kader van de gepresenteerde vignetten zouden omschrijven als goede zorg. De interviews waren semigestructureerd en duurden ongeveer een half uur. Onderzocht is in hoeverre moreel beraad leidt tot veranderingen in het perspectief van begeleiders ten aanzien van beperkingen in het dagelijks leven voor mensen met een matige verstandelijke beperking. Uitkomst van het onderzoek is dat de respondenten geneigd zijn de vignetten op dezelfde manier te evalueren voor en na de moreel beraad sessies. Respondenten waren geneigd vast te houden aan het perspectief dat de toepassing van de beperkingen in het belang van de cliënten was en hen structuur, duidelijkheid en rust gaf. Sommige respondenten hebben echter ten gevolge van het moreel beraad hun perspectief gewijzigd van een focus op het vasthouden aan de beperkingen naar een focus op het aanpassen van de beperkingen om de cliënt meer vrijheid te bieden. Na afloop van het moreel beraad stellen deze respondenten dat zij zich meer bewust zijn van de impact die beperkingen kunnen hebben op een cliënt, vooral als er fysieke dwang wordt toegepast, zoals beschreven in het vignet van de cliënt die fysiek gedwongen wordt om naar haar dagbesteding te gaan. Moreel beraad kan daarom worden gezien als een methode om de kwaliteit van het zorgproces te bevorderen en als een middel om meer aandacht te genereren voor het perspectief van de cliënt. Er is echter meer nodig dan het incidenteel organiseren van moreel beraad. Naast de uitoefening van moreel beraad op een regelmatige basis, zou ook multidisciplinair overleg onder begeleiders en andere professionals over nut en noodzaak van beperkingen, kunnen leiden tot meer sensitiviteit en bewustwording onder begeleiders.

Hoofdstuk 6 – Studie 5

Moreel beraad kan dus worden ingezet als een instrument voor een team van begeleiders om gezamenlijk te reflecteren op morele dilemma's en kan worden beschouwd als een vorm van ethische ondersteuning, zoals we in het vorige hoofdstuk hebben gezien. Wat betreft de feitelijke inhoud van

moreel beraad is er echter weinig onderzoek gedaan. De meeste onderzoeken die zijn uitgevoerd richten zich op de perceptie en waardering van deelnemers aan moreel beraad sessies. Deze studies richten zich dus niet op de eigenlijke thema's die in het moreel beraad aan bod komen noch op de onderliggende motieven en uitkomsten van de besluitvorming. Moreel beraad kan daarom zelfs worden gezien als een 'black box' voor niet-deelnemers. We hebben met het oog hierop de inhoud van de moreel beraad sessies geanalyseerd om bij te dragen aan het openen van deze 'black box'. Binnen het scala aan methoden van moreel beraad, is gekozen voor de dilemma-methode, een gestructureerde en veelgebruikte vorm van moreel beraad in de gezondheidszorg. In deze methode bespreken en analyseren de deelnemers een ethisch dilemma en worden ze begeleid door een gespreksleider. De taak van de gespreksleider is om de dialoog te structureren en te verduidelijken en op deze manier deelnemers te ondersteunen bij het formuleren van hun ideeën, gedachten en gevoelens.

Analyse van de moreel beraad sessies gaf de volgende inzichten in de inhoud van deze sessies. In het vignet van de iPad hebben beide teams besloten om de cliënt na 22.00 uur meer vrijheid te geven in het gebruik van zijn iPad. Deze vrijheid is echter niet onvoorwaardelijk. Als de begeleiders bij de cliënt een ernstig slaaptekort of een verslechtering van zijn fysieke toestand zouden opmerken, zouden ze de beperking opnieuw invoeren door de iPad na 22.00 uur uit te doen. In het vignet van de dagbesteding hebben beide teams ervoor gekozen om de cliënt te overtuigen naar de dagbesteding te gaan. Ze zouden echter niet zover gaan om de cliënt fysiek te dwingen. In plaats daarvan zouden de teams contact opnemen met de familie van de cliënt en ook met de begeleiders van de dagbesteding om een mogelijk motief te onderzoeken dat ten grondslag ligt aan de weigering van de cliënt. In het vignet van de beperking in telefoneren besloten de deelnemers van het eerste team de wens van de cliënt om meer contact met zijn moeder te hebben te ondersteunen. Het team was bereid om contact op te nemen met de moeder van de cliënt of andere familieleden om de mogelijkheden te onderzoeken om het telefooncontact tussen de cliënt en zijn moeder uit te breiden. Het tweede team besloot zich aan de beperking te houden om de relatie tussen de cliënt en zijn moeder niet te

verstoren. Volgens dit team is het onderhouden en in stand houden van een goede relatie tussen de moeder en de cliënt juist in het belang van de cliënt.

Conclusie

De bevindingen van de verschillende studies vertonen coherentie. Begeleiders, mensen met een matige verstandelijke beperking en hun verwanten zijn geneigd in te stemmen met beperkingen in het dagelijks leven van cliënten, maar enkel als deze het welzijn van de cliënten bevorderen. In dergelijke gevallen worden de beperkingen beschouwd als goede zorg. De respondenten uit de studies geven echter ook aan problemen te hebben met sommige beperkingen. Begeleiders geven aan dat zij soms morele twijfels hebben over het toepassen van beperkingen. Hoewel ze wel degelijk beperkingen toepassen, zijn ze er niet altijd zeker van of de toepassing van deze beperkingen wel goede zorg voor hun cliënten betekent. Mensen met een matige verstandelijke beperking zelf zijn kritisch over beperkingen wanneer deze beperkingen hun privacy of waardigheid schaden. Verwanten zijn kritisch wanneer beperkingen worden toegepast zonder dat deze op maat kunnen worden aangepast. Daarnaast onderstrepen verwanten het belang om betrokken te zijn bij het proces van besluitvorming en eventuele toepassing van beperkingen in de dagelijkse zorg voor hun naaste met een matige verstandelijke beperking. Tot slot, nadenken over en reflectie op beperkingen in het dagelijks leven van mensen met een matige verstandelijke beperking vraagt om een gezamenlijk gesprek. Daarom is het aangaan en onderhouden van een dialoog tussen begeleiders, verwanten en cliënten over de toepassing van beperkingen cruciaal in het komen tot verantwoorde gezamenlijke besluitvorming. In deze dialoog is het van wezenlijk belang om het perspectief van de cliënt te betrekken. Moreel Beraad kan een geschikt middel zijn om de hiervoor noodzakelijke sensitiviteit voor het perspectief van de cliënt bij begeleiders te vergroten.

Dankwoord

Curriculum Vitae

Dankwoord

Empirisch onderzoek is minutieus werk, waarbij je niet te snel moet willen, niet meteen groot moet denken of te snel conclusies moet trekken. Dit vergt geduld. Dit kostte mij in het begin moeite, omdat ik vaak snel weer door wilde naar een volgend onderdeel of volgend deelonderzoek. Ook heb ik bescheidenheid moeten oefenen. Op het gebied van onderzoek was ik bij de start van mijn proefschrift een volstrekte nieuwkomer en ik ben dat eigenlijk nog steeds; ik heb veel moeten leren wat wetenschappelijk onderzoek nu eigenlijk inhoudt en welke codes daarbij horen. Dat ik voortdurend aan het leren was, literatuur kon lezen, en teksten kon schrijven, gaf mij energie. De manier van schrijven was alleen heel anders dan ik gewend was. Voor mij was het een overgang van het schrijven van beschouwende stukken naar het schrijven van internationale publicaties waarbij een enkel artikel wel twintig verschillende versies heeft geteld. Nu ligt er dus een dissertatie. Het heeft in totaal zeven jaar geduurd; zeven, een mooi getal met de inherente betekenis van afronding, zoals een week zeven dagen kent.

Op deze plaats wil ik Petri, Cees en Elsbeth bedanken voor hun prettige, aimabele en deskundige manier van begeleiden. Jullie hebben mij voortdurend eraan herinnerd wat empirisch onderzoek nu eigenlijk inhoudt. Petri bedankt voor je niet aflatende positieve energie die je in mijn onderzoek en de Academische Werkplaats Leven met een Verstandelijke Beperking hebt gestopt. Bij blokkades in het proefschrift, heb je gezocht naar wat wel werkbaar voor mij was. Aan mijn wens tot wat meer autonomie heb je gevolg gegeven, zoals je ook meteen bereid was mee te denken in de vormgeving van mijn onderzoek toen een wisseling in functie van zorg naar defensie bij mij aan de orde was. Achter jouw begeleiding, proef ik een sterk sociaal engagement met mensen met een verstandelijke beperking, en met mensen in het algemeen. Hier heb ik veel waardering voor. Elsbeth, dank voor je enthousiaste, professionele, nauwkeurige begeleiding en oprechte geïnteresseerdheid in de ander. Je was altijd bereid tot op detailniveau mee te denken of te schrijven. Je bracht mij ook vaak even terug waar ik te snel wilde. Jij hebt er als begeleider heel veel energie in gestoken en bent blijven doorgaan

met het reviseren van artikelen totdat er iets goeds op de plank lag. Daarnaast hebben we ook veel plezierig persoonlijk contact gehad. Veel dank voor de energie die je in het proefschrift hebt gestoken! Cees, dank voor je suggesties, ideeën, aanbevelingen tijdens het hele promotietraject en dank voor de inbreng van je expertise op het gebied van kwalitatief onderzoek en zorgethiek. Je scherpe analyses brachten mij terug naar de kern en stimuleerden mij om compact en kernachtig te schrijven zonder te veel uitweidingen. Veel dank voor je deskundige en betrokken inbreng! Naast mijn promotoren wil ik ook Maaike Hermsen bedanken die in het eerste anderhalf jaar van mijn proefschrift mijn dagelijks begeleider was. Maaike, wij hebben plezierig samengewerkt, de eerste bouwstenen van de dissertatie gelegd en zijn samen met Petri tot de publicatie van het eerste artikel gekomen.

Collega's van de Academische Werkplaats Leven met een Verstandelijke Beperking, dank jullie wel voor de gezelligheid en de praktische hulp die jullie hebben geboden. In het bijzonder noem ik Sanne, Noud en Sara die een bijdrage aan het proefschrift hebben geleverd door hun expertise in te zetten. Sanne heeft haar kennis ingezet op het terrein van informele netwerken en heeft meegewerkt als mede-codeur in de studie naar verwanten. Noud heeft nauwgezet meegelezen in de inleiding en hierin behulpzame suggesties aangedragen. Sara heeft intensief codeerwerk verricht in de studies over moreel beraad. Hartelijk dank hiervoor!

Het was in het najaar van 2013 dat het promotie-onderzoek naar vormen van vrijheidsbeperking vorm kreeg binnen Elver, destijds nog Fatima Zorg geheten. Elver met toenmalig bestuurder Ernst van Drumpt omarmde het idee van een promotie-onderzoek, en stelde financiële middelen beschikbaar en zorgde ervoor dat ik in ieder geval één dag per week werktijd aan mijn promotie-onderzoek in Tilburg kon besteden. Ik ben zorginstelling Elver hiervoor erkentelijk. Ernst, dank je dat je het onderzoek van het begin af aan hebt gestimuleerd! Dat je namens Elver ruimte hebt willen maken voor wetenschappelijk onderzoek en dat je mij hiervoor de kans gaf. We hebben vaak over het promotie-onderzoek en wat al niet meer gesproken en aan onze gezamenlijke tijd bij Fatima – Elver een vriendschap overgehouden. Na jouw vertrek Ernst, nam bestuurder Irma Harmelink jouw taken over.

Ook Irma wil ik hartelijk bedanken voor de gedegen ondersteuning van het promotietraject. Jij stimuleerde mij resultaten uit het onderzoek te delen met anderen en jij hebt aangemoedigd dat ik binnen de instelling presentaties over het onderzoek hield voor divers publiek, zoals voor behandelaars, managers, bestuurders en begeleiders.

Verder wil ik alle deelnemers aan het onderzoek bedanken voor hun tijd en inzet: bewoners, familieleden van bewoners, begeleiders en behandelaars. Dankzij jullie input heb ik mijn verhaal kunnen schrijven.

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Anne Pier van der Meulen

Curriculum Vitae

Anne Pier van der Meulen werd op 20 december 1968 geboren in Leeuwarden. Zijn jeugd bracht hij door in het Friese dorp Oenkerk gelegen tussen Leeuwarden en Dokkum. In juli 1987 rondde hij het lyceum af in Dokkum, onderdeel van scholengemeenschap Oostergo. Na een half jaar economie gestudeerd te hebben aan de universiteit van Groningen, begon hij in januari 1988 aan zijn studie theologie aan de Theologische Universiteit te Kampen. Medio 1995 rondde hij deze studie af, waarna hij een jaar lang het vak levensbeschouwing gaf op college 't Loo (HAVO/VWO-bovenbouw) in Voorburg.

In 1996 startte hij met zijn werkzaamheden als predikant bij de Vrijzinnige Geloofsgemeenschap NPB te Weesp; in 1999 kwam hij in algemene dienst bij dezelfde Vrijzinnige Geloofsgemeenschap NPB t.b.v. het project Sporing, standplaats Weesp. Als projectfunctionaris gaf hij leiding aan dit bureau voor religieus-culturele oriëntatie. Ook stelde hij zich via Sporing beschikbaar als predikant voor rand- en buitenkerkelijken om voor te gaan in huwelijks-, of uitvaartdiensten. Gedurende de vijf jaar die hij bij de Vrijzinnige Geloofsgemeenschap NPB werkte, verzorgde hij voor de groepen 7 en 8 het vak wereldgodsdiensten op alle openbare basisscholen in de regio Weesp-Muiden. In 2001 stopte het project Sporing, waarna hij een jaar lang als leerkracht (zij-instromer) heeft lesgegeven aan groep 7 en 8 van de Vrije School in Zaandam.

In augustus 2002 werd hij benoemd tot predikant van de Hervormde Gemeente Oude en Nieuwe Niedorp in Noord-Holland (later Protestantse Gemeente Oude en Nieuwe Niedorp). Vijf jaar later werd hij predikant in Gendt en Doornenburg, twee dorpen gelegen in de Overbetuwe ten noorden van Nijmegen. Na dit predikantschap van vier jaar in deze Gelderse dorpen stapte hij over naar de gehandicaptenzorg, waar hij in 2011 als geestelijk verzorger aan het werk ging bij de stichting Fatima Zorg. Na een fusie met de Schreuderhuizen ging de naam over in stichting Elver. Als geestelijk verzorger bij Elver was hij aanspreekpunt voor cliënten, medewerkers en familieleden van cliënten, voor individuele vragen over zingeving en ethiek. Ook begeleidde hij groepsbijeenkomsten voor cliënten,

waarin zij de gelegenheid kregen hun verhaal te vertellen. Daarnaast was hij voorganger in uitvaartdiensten voor mensen met een verstandelijke beperking als wel in de gewone zondagse vieringen. Als geestelijk verzorger was hij ook contactfunctionaris ethiek. Hij begeleidde diverse vormen van moreel beraad waar zowel cliënten, medewerkers, familieleden of vrijwilligers bij betrokken konden zijn. Geregeld werd de inhoud van het moreel beraad gekleurd door het thema vrijheidsbeperking. Op 1 januari 2014 startte het promotietraject gericht op dit thema. In de eindfase van zijn promotie-traject verruilde Anne Pier zijn functie als geestelijk verzorger in de gehandicaptenzorg voor een functie als geestelijk verzorger bij defensie, waar hij op 1 januari 2019 in dienst trad.